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ABSTRACT

This final report presents the outcomes of Project INSITE, a family-centered home intervention model designed to provide training to early intervention/childhood professionals working with infants and young children with multidisability sensory impairments and their families. In the INSITE model, an early intervention professional visits the home of a child with sensory impairments and additional disabilities to work with the family. Parents and the professional work together as team members in determining goals, writing/reviewing the Individualized Family Service Plan or the Individualized Education Program, carrying out and monitoring activities, and preparing for transition to school programs. The report presents information on the goals, objectives, and activities of the project over the 3-year grant period. The conceptual framework for the project is discussed. A complete description of the model, replication sites, dissemination activities, and training activities is provided. The methodological/logistical problems that were faced and how they were solved are reviewed. The evaluation findings of the project are presented, and data from a validation study are included (1991-92, n=52 children; 1992-93, n=81 children; 1993-94, n=34 children). The project's impact is noted and future activities are discussed. Appendices include: sample newsletters, a family resource notebook, the INSITE Model overview, tables of contents of a family resource notebook and two volumes on the INSITE Program, a sample agenda of an INSITE workshop, an INSITE training format overview, and detailed INSITE data reports. (Contains 19 references.) (CR)

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# FINAL REPORT

to

**U.S. Department of Education**
**Office of Special Education Programs**
**Early Education Program for Children with Disabilities--Model Inservice Training Projects**

**CFDA 84.024D**

**by Project INSITE**

**Outreach Services to Stimulate Home-Based Services for Infants, Toddlers, and Preschool Age Children with Multidisability Sensory Impairments and Families**

**Award #H024D20022**

**SKI-HI Institute**
**Department of Communicative Disorders**
**Utah State University**
**Logan, Utah 84322-1900**

**June 29, 1996**

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## II. Abstract


Outreach Services to Stimulate Home-Based Services for
Infants, Toddlers, and Preschool Age Children with
Multidisability Sensory Impairments and Families

**Project INSITE**

Don Barringer, Director — Dorothy Johnson, Outreach Coordinator

Project INSITE is a family-centered, home intervention model, designed to provide early intervention/childhood professionals serving preschoolers, ages birth to five, with sensory impairment with additional disabilities with the training needed to better serve these young children and their families. Project INSITE was developed as a U.S. Office of Special Education Early Education demonstration model between 1981 and 1994, became an Outreach program in 1984, and was validated in 1989 by the Program Effectiveness Panel, National Diffusion Network, U.S. Department of Education.

In the INSITE Model, an early intervention professional, or parent advisor, goes to the home weekly to work with the family of a child who has sensory impairments and additional disabilities. The parent advisor uses both their training in the INSITE model and the INSITE Resource Manual to guide them as they work with these children and families. Under this system, the parents and parent advisor work as team members with other appropriate professional personnel in determining goals, writing/reviewing the Individualized Family Service Plan (IFSP) or Individualized Educational Program (IEP), carrying out and monitoring activities, and preparing for transition to school programs.

The goals and activities of the INSITE Outreach project focused on: meeting the unique developmental needs of very young children who are multidisabled and sensory impaired, providing a complete delivery system of family centered intervention for infants, toddlers, and preschoolers who are multidisabled and sensory impaired and their families, utilizing an innovative awareness and training approach to meet the changing audiences of direct service providers, developing state-of-the art materials which support early interventionists and the families they serve, providing training for local INSITE trainers thereby enabling them to provide INSITE training to new professionals in programs throughout their state, and developing/implementing a system of providing follow-up and technical assistance to sites.

The population INSITE serves continues to grow. This is due to a myriad of societal changes, including drug use during pregnancy, teenage pregnancy, and medical advances in neonatal care. Letters of request for services from states and agencies echo this growing need for INSITE training, materials, and assistance in developing effective early intervention services for these children and their families. The establishment and continued support of Outreach Services to Stimulate Home-Based Services for Infants, Toddlers, and Preschool Age children with Multidisability Sensory Impairments and Families provides a mechanism family service providers and the families they serve can utilize to exchange information and techniques which have been proven to further the development of these children.

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## IV. Final Report on Goals, Objectives and Activities of the Project Over the Three Year Grant Period

### Objective #1

To coordinate awareness, planning, and replication activities with the state lead agencies for part H of the IDEA and the state educational agencies.

State lead agencies were contacted at each step of the process of awareness, needs assessment, planning, and training. INSITE staff have worked with state coordinators to facilitate the development of systems in the states for continued implementation, including the development of systems which will increase local training capacity and the flow of critical information to facilitate long-term continuation of implementation/training activities.

For the grant and grant extension period, systems development for long-term implementation of the INSITE Model, through on-site awareness conferences designed to strengthen and/or encourage the formation of state and/or regional steering/planning committees were conducted in AK, IA (EZone), IL (EZone), IN, LA, MI (EZone), NJ, NY, SD, RI (ECommunity), and WI. In addition a multi-state awareness meeting was held in Utah June 10-12, 1993 for state coordinators from MN, WI, NC, WY, and IN. This provided the SKI-HI Institute with an efficient way of connecting with several states and presenting its programs, while bringing together key people from each of the target states so that they could confer with each other concerning their states' needs and discuss the ways in which INSITE could be implemented within their state. Three of these five states, NC, IN, and WI, subsequently received individualized training and/or awareness services.

To promote widespread awareness of the INSITE model, the project continues to disseminate awareness materials, including brochures, training information sheets, newsletters, descriptions and prices of materials. Additionally, three issues of the SKI-HI Institute Newsletter, in which INSITE has a prominent part, were printed and distributed each year. Each issue of the newsletter has reached more than 2,500 agencies/individuals. The newsletter includes articles on new projects and products of INSITE, the activities of INSITE replication sites around the country, INSITE training activities, as well as new materials relating to INSITE.

See Appendix A for a sample newsletter.

**Objective #2**

To create appropriate public, professional, and agency awareness of the need for services to children with multidisability sensory impairment and their families and of the services available through Project INSITE.

INSITE promotes public and professional awareness by responding to all requests for information, by speaking at conferences, and by disseminating materials nationwide through its network of replication sites. Through this well developed awareness and dissemination program the following were accomplished:

a. Distributed an *awareness brochure* and a 15 minute *awareness video* which stimulated program interest by providing a brief program overview.

b. Shared implementation information in the *Parent Advisor Network* at regional conferences and local meetings. Over the years, the network of INSITE part-time and full-time parent advisors (direct service providers) has grown to over 550.

c. Shared information in the *Certified Trainer Network* via newsletters and conferences as well as through Basic Training delivered by National Trainers and by the local training systems firmly established in many states.

d. Produced *INSITE materials* through research and product development. Announced availability of these products in the *SKI-HI Institute Newsletter* which reached over 1,200 people, 3 times a year. *INSITE products* were made available to the those working in the field and to parents through a distribution company called Home Oriented Program Essentials, INC., (HOPE). Through HOPE INC., parents and professionals could/can access INSITE materials at a very reasonable cost.

e. Disseminated Awareness and other Project INSITE materials directly to the field by the project through the mail as well as at national, regional, and local conferences and awareness sessions.

f. Presented information about the INSITE program, materials, and data at various conferences.

g. Conducted 11 *Awareness Conferences*.

## Objective #3

To develop and disseminate resource, training, and awareness materials for parents and professionals.

Project INSITE at the SKI-HI Institute has a product development division and a national network of sites for field testing new curriculum programs and materials. The project follows a procedure established at the SKI-HI Institute, which begins with recognizing a need in the field. Based on need, the product is conceived and money is requested in the next budget. A prototype of the materials is developed and tested throughout the INSITE network. Revisions are made and a final master is produced. The product is then distributed in the INSITE network. This process was used throughout the three years of the project.

Based on need indicated by INSITE users, project resources helped to develop the products listed below during the 1992-95 grant period.

1. **Resource materials for parents and professionals.**

   A draft of the INSITE Parent (Family) Resource Notebook has been completed. Each section of the notebook was read and critiqued by active parent and parent advisor readers across the country. Sections were then edited to reflect the comments of the readers. The completed notebook was then published in draft form and presented to a select group of parent advisors in Utah for field testing. The feedback which the Utah parent advisors will provide in Summer, 1996, will be used to make the final modifications for the resource notebook. The final notebook will be printed and distributed through HOPE, Inc., to parent advisors nationally.

   This resource notebook provides families with a child who has multisensory disabilities with an organized way of keeping and organizing information. It is designed to empower families to become participating members of the early intervention team. See Appendix B for a sample Coversheet and Table of Contents for the Family Resource Notebook. (Note: Translation of the notebook into Spanish will be completed upon receipt of final modifications based on the Utah field test.)

   Two sections of the new Core Resource Manual, Foundations of Partnershipping & Enhancing the Parent/Parent Advisor Partnership have been completed. This manual is a resource for parent advisors and parents of young children with special needs who are working together in early intervention programs. The manual is for both the parents and parent advisor as they learn and work together as a team in early home programming.

2. **Training materials, both printed and audio-visual.**

Work was completed on new video clips which have been incorporated into INSITE training. These training clips include information on tactile signing for communication with children who are sensory impaired with additional disabilities, particularly those with a dual sensory impairment and include information on tactile communication, primitive signaling, coactive signing, and interactive signing.

Additionally, filming and initial editing has been completed on a new videotape to be used in training on functional vision assessment done in the context of daily routines. The completed program will be available in the fall, 1996.

Other training tapes that have been completed include: A Case Study Of A Child Who Is Sensory Impaired With Additional Disabilities and A Family Centered Home Visit.

3. **Awareness materials.**

The INSITE audio-visual overview has been revised to reflect program development. The printed in-depth INSITE overview and description of trainers has been updated. In addition, awareness materials designed to fit the needs of specific implementation sites across the nation have been developed and/or adapted for site specific presentations.

4. **Instructional and evaluation materials for training.**

With NEC*TAS assistance, a specialist on adult learning techniques, Larry Edelman, spent time in May 1995 with project staff and reviewed a significant portion of the INSITE training materials. As a result of his consultation, INSITE training materials underwent a major revision to incorporate more adult learning principles, strategies, and activities. These revised training guidelines, handouts, and transparencies were packaged in notebook form. The availability of the new training materials packet was announced in Trainers' Tidings, the newsletter for all local and national trainers. See Appendix C for a sample Table of Contents from Trainers' Tidings. The new training packages have been distributed to the 10 national trainers, and at the 1996 local INSITE trainers' certification workshop. A Home Study manual for use in INSITE training was also developed during the course of this grant.

Updating of training guidelines, handouts, and overhead transparencies has been an ongoing activity throughout the project. INSITE national trainers met at Utah State University in January of 1995 to review training materials and provide valuable input for future changes/adaptations in training format and materials.

5. **Disseminate new materials through the INSITE network and marketing.**

The availability of the Parent (Family) Resource Notebook will be announced fall, 1996 in the SKI-HI Institute Newsletter and will be available to the INSITE network through HOPE, Inc., a distribution company which markets new products.

## Objective #4

To collaboratively assess state and local needs, stimulate agencies to commit resources to development and implementation of INSITE services and develop and carry out a plan for implementation.

The project has developed an innovative statewide/region-wide awareness and dissemination conference process. The project was able to use the resources of the State Facilitator and the State Office of Education and/or Health Special Education Program to locate the appropriate target agencies and people to disseminate and facilitate the replication process. Through close work with the above facilitators, the project came to understand the needs and goals of states in the area of early intervention, and to help meet those needs. Part H and Section 619 coordinators are essential to this new process in that all early intervention efforts *must* be coordinated with them. INSITE requests that within the state, these coordinators form an advisory or steering committee to assist in selecting individuals to be trained, determine dates and locations for training, and provide the necessary single source coordination for INSITE implementation in their state. This statewide coordination is critical to successful implementation and long term systemic change, a major goal of Project INSITE.

The activities associated with site development and replication which were carried out during the project period are listed in sequential order below:

a. Worked with state lead agencies and local agencies to assess needs and the match with INSITE.

b. Located potential replication sites. If there was sufficient interest in the INSITE Model, the state lead agency or agencies wrote a letter of request for outreach services. The state lead agencies then acted as the coordinators between INSITE and local service agencies. Each local agency sent a letter of request indicating (1) the current status of services to children with sensory impairments with additional disabilities and their families and the need for INSITE, (2) a

commitment to using INSITE for at least a year after training, (3) an estimate of the number of personnel to be trained, and (4) an estimate of the number of families and children expected to receive INSITE services.

c. Selected sites for replication. If the agency met the criteria for replication, the agreement was negotiated. The following selection criteria were used:

1. Personnel have a positive attitude towards replication.
2. Personnel and financial resources will be committed to implement the program.
3. The agency is willing to share in or pay for outreach costs.
4. There is evidence of commitment to continue services after outreach assistance ceases.
5. There is a demonstrated need for the outreach services as evidenced by numbers of unserved or underserved infants, toddlers, and preschool age children who are multidisability or dual sensory impaired.
6. Agency personnel have made an official request for outreach services.
7. Agency personnel agree to provide equal access and treatment for all children who are members of groups that have traditionally been underserved, including minority, low-income, and rural families, and to provide culturally competent services in local areas.
8. The replication conforms to the state's plan for early intervention and preschool and related services and the state lead agency is aware of or coordinating the replication activities.

d. Coordinated with and provided information to state lead agency and local agency administrators and supervisors for program development. When a new agency made a commitment to replicating INSITE, the INSITE project worked with the agency's staff to ensure optimal development of the program. INSITE provided guidelines in development of the program, recruiting personnel, deciding who should attend training, and coordinating INSITE implementation with states' fulfillment of the IDEA.

The INSITE coordinator/trainer arrived one day prior to the training and met with the local coordinator. During the series of two training sessions, the trainer/coordinator provided technical assistance to personnel as they prepared to implement the model. Following the last training session the trainer/coordinator remained for an on-site technical assistance visit.

e. Provided materials for replicating agencies. Each replicating agency obtained a basic set of materials necessary for INSITE service delivery for each parent advisor working with families. The trainer/site coordinator worked with the disseminator to be sure the manuals were delivered prior to training.

During the 3 years of this grant, replications or scheduled replications resulted from awareness activities in the following states: AK, CA, IA (EZone), LA, NC, PA (ECommunity), RI (ECommunity), VA, and WI. In many states, there were several replications per state. Initial plans for INSITE training and implementation were then put into place for each of these states. Each state committed financial resources through the combined efforts of their lead agencies (i.e., Part H, 619, VI-C, NDN state facilitators) and the local replication agencies.

**Objective #5**

> To provide training to replication agency personnel for implementing the INSITE Model, and to prepare and equip certified trainers in order to ensure continuity of INSITE services.

Typically, a trainer/coordinator and a co-trainer are selected by the INSITE Outreach staff to work with a state (or site). The trainer/coordinator conducts much of the pre-planning for this workshop by phone with the state contact person for INSITE. Once all preparations have been made and participants selected, the trainer/coordinator and a co-trainer conduct the two on-site training sessions at the site for a total of six days, with the size of the workshop being limited to 25-30 participants for maximal training benefit. When the training is offered as a Homestudy course, modifications to the onsite schedule are made in order to allow for the homestudy portion of the course.

Participants learn how to make optimal use of INSITE programming in order to plan a coordinated individualized program for a family. The trainers make use of the expertise of the participants in practice and presentations. They also assist local personnel in determining ways the model can be incorporated easily into their existing programs.

A variety of teaching methods and materials are used in the training workshops. These include video tapes, slides, overhead transparencies, handouts, demonstration, lecture, discussion, small and large group work, practice, role playing, chalkboard, and direct work from the manuals. The two trainers take turns in presenting.

A post-training conference meeting takes place immediately following the last training workshop. Evaluation of training is completed through evaluation at the end of the workshop and a six-month follow-up.

The trainees can obtain college credit for workshop participation through Utah State University's continuing education program. See Appendix D for an introduction to the INSITE Model, Table of Contents from the INSITE Curriculum, 2nd Edition, and a sample agenda.

During this grant period, INSITE Outreach conducted basic training workshops for professionals/parent advisors in AK, CA, IA, LA, PA, RI, VA, and WI, with CA, IA, and LA conducting continuation or multiple trainings during the grant. In addition, trainees came from many different agencies within each of those states, and many became state certified state trainers during the years that followed their initial training.

**Objective #6**

To enhance the capacity of agencies to continue providing quality services by conducting follow-up technical assistance activities.

a. Once the steps described under objective two for site development and replication have taken place and the first basic training has been completed, project INSITE continues to work with the state and its agencies as needed and requested. Year two training for professionals from new agencies within a state is provided. Consultation by phone and onsite visits by project staff is frequently made.

b. Local State Trainers. The continued integrity of the INSITE model depends in large part on maintaining the quality of the training delivered to new users of the model. INSITE has developed a systematized program for preparing, certifying, and updating trainers at the national and local levels. One of INSITE's main goals in any state is to facilitate the establishment of a fully operational INSITE state trainer system.

A prospective trainer must have experience in working as an INSITE parent advisor and approval of the employing replication program. After meeting these and other requirements, the prospective trainer must successfully complete about 15 hours of intensive training. The new trainer is then authorized to conduct INSITE training in her or his region or state. INSITE conducted yearly trainer's training workshops for local/state trainers during the 1992-95 grant period. Participating states included CA, GA, IA, LA, NM, OH, PA, and WV.

INSITE publishes a trainers' newsletter, maintains a roster of certified trainers, and includes sessions for trainers at national and regional SKI-HI Institute conferences.

c. National Trainer System. After maintaining ongoing certification, a locally certified INSITE trainer may apply to become certified at the national level. With final approval by Project INSITE and his/her local program, a new national trainer can become fully certified and eligible to conduct training outside the local region or state. INSITE provides a training and orientation session to new national trainers. A new trainer is then teamed with an experienced trainer for at least one national workshop series.

INSITE monitors the performance of its trainers through workshop evaluations. All national basic training and trainer's training workshops are evaluated by the participants with a standard evaluation tool which is analyzed and summarized following each workshop by the project evaluator and coordinator. Data from evaluations are discussed by the INSITE staff and valid suggestions are relayed to trainers and incorporated into subsequent workshops.

INSITE workshops continually receive above satisfactory participant evaluations. A team of two trainers conducts INSITE training. The trainers are selected on the basis of schedule availability, individual strengths, and location. Every 2 to 3 years, INSITE brings all national trainers together for essential update and re-orientation. This was last done in January of 1995, when the national INSITE trainers were brought in to the project headquarters in Logan, Utah for a 3-day weekend session.

## Objective #7

To evaluate the effect of the INSITE model on child and family progress, and to evaluate the effectiveness of the outreach process.

INSITE Outreach collects information on results of the Outreach process and on child and family progress in INSITE programming. An evaluator analyzes and interprets the information and evaluates the data collection process itself on an ongoing basis throughout the grant period. In this way, ongoing adjustment and improvement is possible. Evaluation results are reported to the field and to the U.S. Department of Education.

The outreach efforts are also evaluated continually to meet the needs of the audience served. These audiences include the statewide Part H and Section 619 coordinators, the State Facilitators, the direct service personnel trained, and the agencies they represent, and the children and families served by Project INSITE. Direct and indirect evaluation methods are employed to evaluate the process.

The Project maintains files of all replication sites and a listing of these sites, with

addresses, contact person, and telephone. Every year, INSITE mails a simple survey form to all replication sites to determine current status of implementation and to update/correct address, telephone number and name of contact person. The form is on a self-addressed, postage-paid postcard. Sites are asked to complete and return the form. Records and lists are then updated. Through this maintenance of site records come future local trainers, future site affiliations for mutual benefit, and future opportunities to gain child and parent data. These files also assist the project in evaluating the ongoing use of INSITE.

INSITE collects demographic and child/parent progress data from INSITE agencies across the country. Agency personnel are trained in assessment and data collection and entry. INSITE provides a demographic and child/parent progress data form for recording. The agencies obtain yearly pre- and post-treatment profiles on the Callier-Azusa Scale showing child progress. The data are sent to the SKI-HI Institute Data Center, where they are analyzed. This databank provides valuable information to replicating agencies which is useful for program evaluation, funding continuation, and program improvement. It is also an excellent source of demographic information on infants, toddlers, and preschoolers with sensory impairments and additional disabilities, and is a potential data base for future research. INSITE staff produce an annual National INSITE Data Report based on these data. See Appendix F for the 1993-94 National INSITE Data Report.

Monitoring is a means by which INSITE determines the implementation status of the adopting agency or individual. Monitoring is conducted by correspondence, questionnaire, and telephone consultation. Information obtained through monitoring serves two important purposes: (a) it gives an indication of needs the agency or individual has for refinement of its implementation and how closely it is able to adhere to the model, and (b) it indicates the effectiveness of outreach training and INSITE technical assistance to date.

## V. Conceptual Framework For The Project

INSITE outreach focuses on two major areas of need. The first area has to do with the handicapping conditions that the service model treats and associated service delivery model needs. The second area relates to effectively transferring an early intervention model through outreach to local agencies, and subsequently to implementing effective services for children and families.

These needs will be discussed below. How the Project met these needs will be discussed in section seven.

### A. The Effects of Multidisability Sensory Impairments on the Child and Family

The child served by INSITE programs is defined as one who is deaf-blind, blind or vision impaired with other disabilities, or deaf or hard of hearing with other disabilities. These sensory impairments are perhaps the least understood of all handicaps, and the most devastating to the development of the child. The cross-developmental effects of a combined sensory loss are staggering (Collins, 1988). The effects are not merely additive, but multiplicative and cumulative (McInnes & Treffrey, 1982).

Vision and hearing are the primary senses that put a child in touch with the world beyond his or her reach and through which the child can most efficiently learn through modeling. When one or both of these senses is impaired, opportunities for secondary and tertiary learnings are severely restricted. Communication deficits and mobility limitations are two obvious consequences of a multidisability sensory impairment. Other delays typical in these children are disruptions in fine motor, cognitive, and social-emotional development (Bullis & Bull, 1986; Chen, Friedman, & Calvello, 1988; Correa, 1987; Fox, 1983; Gothelf, Rikhye, & Silberman, 1988; Murdoch, 1986; Watkins, 1983; Writer, 1984.)

The effect of the infant or child with a multidisability sensory impairment (MDSI) on the family can be one that adds psychological and financial stress. The family may be in need of guidance and support (Smith, 1988). Establishment of meaningful communication between parent and child as well as a nurturing environment are critical. Extensive time spent in ICUs, loss of the idealized child, infant unresponsiveness, extensive medical intervention, lack of sensitivity by professionals and many other abnormal occurrences combine to compound stress

to family relationships. Parents require time to adjust and organize their lives after the birth of a child with a disability.

**B. The Need for Intervention**

The effects of multihandicapping conditions on the developing child and the family create a critical need for intervention. Project INSITE recognizes this and addresses five key needs. These needs and the INSITE approach to meeting them are strongly supported by research, as described briefly below. References are in Appendix G.

1. The first is the need for *early home intervention*. Infants and toddlers with sensory impairments with additional disabilities must receive early intervention if their development is to be facilitated. The home is widely recognized as the place where early stimulation should occur, if possible. Daily experiences that are ideal for stimulation occur in this natural environment, such as mealtime, dressing, and play. There are additional advantages of the home as the primary intervention setting. Activities can be adapted to the culture and values of the family. Other family members can be involved. Home visits can provide a less threatening setting for the family, give a more realistic picture of family dynamics and emotional needs, and provide a comfortable atmosphere for support. Home visits seem to result in a higher rate of parent participation (Schow & Watkins, 1989).

2. The second is the need for *family-centered intervention*. A family centered approach to intervention is necessary, not only because of legal mandates (Part H of the Individuals with Disabilities Education Act (IDEA)), but because it will facilitate (a) an understanding of the child as part of a family system, (b) the identifying of family concerns and priorities for service, (c) the identifying of family resources and supports that promote family adaptation, and (d) the expanding of a base for evaluating services (Bailey & Simeonsson, 1988).

3. The third is *the need for services that address all aspects of the child's development and environment*. The IDEA stipulates attention to and service provision for all aspects of the child's life. The effects of sensory impairments with additional disabilities on various developmental areas were discussed earlier. The assessment of child characteristics and needs in all domains (i.e., communication, motor, socialization, adaptation, cognition, sensory) must be culturally competent and adapted to each individual family and the environment in which they live and function (Anderson & Goldberg, 1991; Barnett, Macmann, & Carey, 1992; LeLaurin, 1992). Child skills, needs, and characteristics likely to affect family functioning must be determined. Developmental habilitation and stimulation must then be given as appropriate (Bailey & Wolery, 1989).

4. The fourth is *the need for transitioning the child from home to school-base programming*. A smooth and effective transition must involve the parents, parent advisors, teachers and other members of the multidisciplinary team who address the gathering of information from and about the family, child assessment, staff/parent knowledge of programs, parent involvement, cooperative decision making, program modification and ongoing communication. This ensures continuous age-appropriate service for the child and positive, productive program-change experiences for family members.

5. *The need for cost-effective early intervention*. Special education programs for preschool children with disabilities must be cost-effective. A comprehensive review of the research in this area indicates that early intervention programs in general provide long-term human and economic benefits. For example, an extensive review was conducted on the costs of special education based upon age of entry into the program. The data indicated that delaying services resulted in more children requiring more special services at higher costs (Colorado Department of Education, 1984). Early education programs in general have been shown to be cost-effective; the INSITE model, in particular, has been verified as a cost-effective service delivery model. See Appendix G for references to this section.

## C. Concepts Underlying the INSITE Outreach Project

The INSITE early home intervention program was developed to meet the needs of the family and the child with sensory impairments with additional disabilities. There is a further need for a system to transfer that effective program to state and local agencies which serve children and families. State and local educational agencies, Part H and Section 619 coordinators continue to request INSITE training and implementation assistance. INSITE Outreach provides an effective process for awareness, dissemination, training, technical assistance, evaluation, and product development which meets their needs.

With the support of the EEPCD, the INSITE Model has been adopted throughout the United States by specialized programs serving very young children with sensory impairments and additional disabilities and their families. With the implementation of P.L. 99-457 and P.L. 102-119, children with low incidence disabilities are now also beginning to be served within early intervention/early childhood programs for all infants, toddlers and preschoolers with disabilities. It should be noted that except for the larger metropolitan areas, there are usually only a few children with sensory impairments with additional disabilities in each local early childhood or parent-infant program. This change in service setting has opened a new arena and demand for

INSITE Outreach services.

When the INSITE service model is delivered through local school districts and other early intervention agencies typical in today's service delivery, the personnel who provide the direct services are typically not those with specialization in sensory impairments combined with other handicapping conditions. Instead, they have generally received cross categorical training with only limited exposure to sensory impairments. In addition, access to other professionals who might have experience and training with this low incidence population is often limited. Thus, INSITE training for personnel in these programs becomes vitally important and enables them to provide more appropriate services to children (birth to 3) with sensory impairments with additional disabilities and their families.

In responding to the desire for coordinated statewide services and systemic change, INSITE Outreach conducts awareness and dissemination, and all planning, training and technical assistance, through close cooperation with state coordinators of education and coordinators of Part H and Section 619 programming.

Project INSITE Outreach offers critical training components to school districts and other agencies serving infants, toddlers, and preschoolers with sensory impairments and additional disabilities. These components include how to work with parents and other caregivers in the home and other settings outside the school. The training includes specific techniques and activities to use with this population as they relate to their unique needs. These elements included in the training are necessary to ensure optimal programming and to ensure that *all* children will enter school ready to learn. It is imperative that children with sensory impairments and additional disabilities receive the programming and materials offered through Project INSITE Outreach, for these children are part of the realization of this goal.

## VI. Description of The Model, Replication Sites, Dissemination Acitivites, and Training Activities

### A. Description of Proven Demonstration Model--The INSITE Model

The INSITE Model is a family support model for families of infants, toddlers, and preschoolers with sensory impairments with additional disabilities. The rationale for designing a program specifically for this population is that a multisensory or multidisability sensory deprivation has a profound effect on the child and family that cannot be addressed adequately by non-categorical programming.

INSITE model services are delivered in the home to the family and in alternate day care settings to other significant caregivers. An early intervention professional, called a parent advisor, goes to the home on a weekly basis to work with the families, providing support and information, and enhancing the family's development of skills to facilitate their child's development. The parents determine their resources, priorities, and concerns. With the parent advisor, they develop family/child goals and select experiences and activities in which to practice new skills. The parent advisor shares information and models skills for the parents with the child, keeping in mind the unique structure and environment of the family. The parents then use the new information and skills to facilitate development in the child as they interact with him or her.

The parent advisor also helps the family facilitate interdisciplinary coordination among all professionals and agencies serving the family. The parents and parent advisor work as team members with other appropriate professional personnel in assessing the child, writing and reviewing the IFSP, carrying out and monitoring goal-oriented activities, and designing transition procedures.

The resource manual which the parent advisor uses was developed by INSITE staff. It has been designed around several major developmental areas. The Communication Program enables the family to establish a communicative relationship which provides a base for the child's developmental progress. The Hearing Program helps the parents manage their child's hearing aid usage and facilitate auditory development. The Vision Program helps the parents understand visual loss and facilitate the child's visual development. The Motor Development Program assists parents in facilitating the child's use of his or her motor capacity. The

Cognition Program helps parents foster cognitive development in the child. The Developmental Resources Section provides additional information and activities for daily care/self care, gross and fine motor development, and social-emotional skills. The Parent Readiness guide of the resource manual helps the parent advisor make an ecological observation and, along with the parents, discover and access resources to meet family-identified concerns. Together, the parents and parent advisor decide which developmental areas to work in, then decide on goals, objectives, and facilitative activities appropriate to the family. They keep records of their progress and the progress of the child, and make adaptations as needed.

In its essence the INSITE Model is a family-centered model. The child is identified at the earliest possible age and the parents receive support, information and training concerning the disabling conditions, special considerations about parenting their child, and working collaboratively with providers of services. The parent advisor adapts the programming as appropriate to cultural background, values or other considerations. The strength of an INSITE home-based program is the effective involvement of the family in all aspects of the service delivery model. The parents fully participate in establishing family focused goals and the IFSP. They participate in service coordination. They periodically review progress to establish new goals, make a communicative methodology decision, and help decide when program goals are met and home services are no longer needed. They cooperate in the transition of their child from home programming to center-based programming. As a result of early intervention, the family attains an acceptance of the child and the disabilities; understands and uses the programming needed by the child; establishes a communicative, nurturing environment for the child; and is equipped to continue service coordination as the child transitions to other service settings.

The three major components of the INSITE model are Administration, Direct Services to the Family, and Supportive Services. Figure 1 on the following page illustrates the complete INSITE Model.

Figure 1

## THE INSITE MODEL

### ADMINISTRATION

| Identification | Family Directed Assessment | Program Management | Training and Supervision | Transition |
|---|---|---|---|---|
| Screening<br>Public Awareness<br>Referral System<br>Intake System | Multi-Disciplinary Assessment of the Child and of Family Resources, Priorities, and Concerns<br>Family Focused Interview<br>Family Goal Setting<br>IFSP<br>IEP | Coordination with Statewide System<br>Staff Selection<br>Service Delivery Model<br>Service Coordination<br>Interagency Cooperation<br>Program Evaluation<br>Home Visit Procedures<br>Budget | Staff Training<br>Inservice Training<br>Supervision System | Service Option Planning and Development<br>Transfer of Information<br>Adherence to Local Procedures<br>Post-Placement Follow-up |

### DIRECT SERVICES TO THE FAMILY

| Family Readiness | Communication Development for the Family | Developmental Areas | Team Management | Family Support |
|---|---|---|---|---|
| Caring for the Child<br>Meeting Family Survival Needs<br>Emotional Readiness for Information | Creating an Environment that Fosters Communication<br>Informal Communication<br>Formal Communication<br>Other Communication Modes | Vision Program<br>Hearing Program<br>Motor Program<br>Cognition Program<br>Self Help, Social and Tactile Skills | Parent-Professional Partnership<br>Consultation and Planning<br>Periodic Assessment<br>Periodic Staffings | Psycho-Emotional Support<br>Accessing Services<br>Working with Intervener<br>Cultural Competence |

### SUPPORTIVE SERVICES

| Medical | Educational/Clinical | Logistical | Psychological | Community |
|---|---|---|---|---|
| Otolaryngology<br>Ophthalmology<br>Pediatrics<br>Nursing | Audiology<br>Physical Therapy<br>Occupational Therapy<br>Speech/Language<br>Vision<br>Hearing<br>Orientation and Mobility | Video Equipment<br>Hearing Aid Loan System<br>Parent Materials<br>Adaptive Equipment<br>Parent Library Loan<br>Low Vision Aid Loan System<br>Toy Lending Library | Consultative<br>Parent/Family<br>Parent Advisor<br>Parent Groups | Church<br>Cultural Resources<br>School<br>Respite Care<br>Mental Health<br>Social Services<br>Foundations |

| Financial | Intervener | Transitioning |
|---|---|---|
| Public Service Agencies<br>Private Agencies | Selecting, Training and Using Intervener | Assistance to Parents<br>Preparation of Child |

## B. Description of Outreach Model

The INSITE Outreach design includes all the activities specified for EEPCD, Outreach Projects and is organized as follows to facilitate optimal capacity building:

1. Coordination with Lead Agency for Part H and with State Educational Agency for Preschool Special Education.

2. Awareness and Dissemination
   Product Development and Dissemination

3. Site Development and Assistance in Replicating the Model

4. Training
   Follow-Up Activities and Technical Assistance
   Evaluation

The above activities are described in further detail throughout Section C which reports the accomplishments made for each of the objectives and components of the model. Figure 2 on the next page depicts the flow of outreach services to agencies in a sequential manner. However, some activities are ongoing and not specific to an implementing site. Please note that all services to sites begin through coordination with lead agencies.

Following Figure 2 is Figure 3 which illustrates the replication process an agency experiences, from primary awareness to full integration into a statewide system. Figure 2 shows how the activities and procedures described above are used to accomplish replication. INSITE has developed an Implementation Process Checklist which staff members use at important checkpoints to monitor this process.

Figure 2

# INSITE Outreach Design

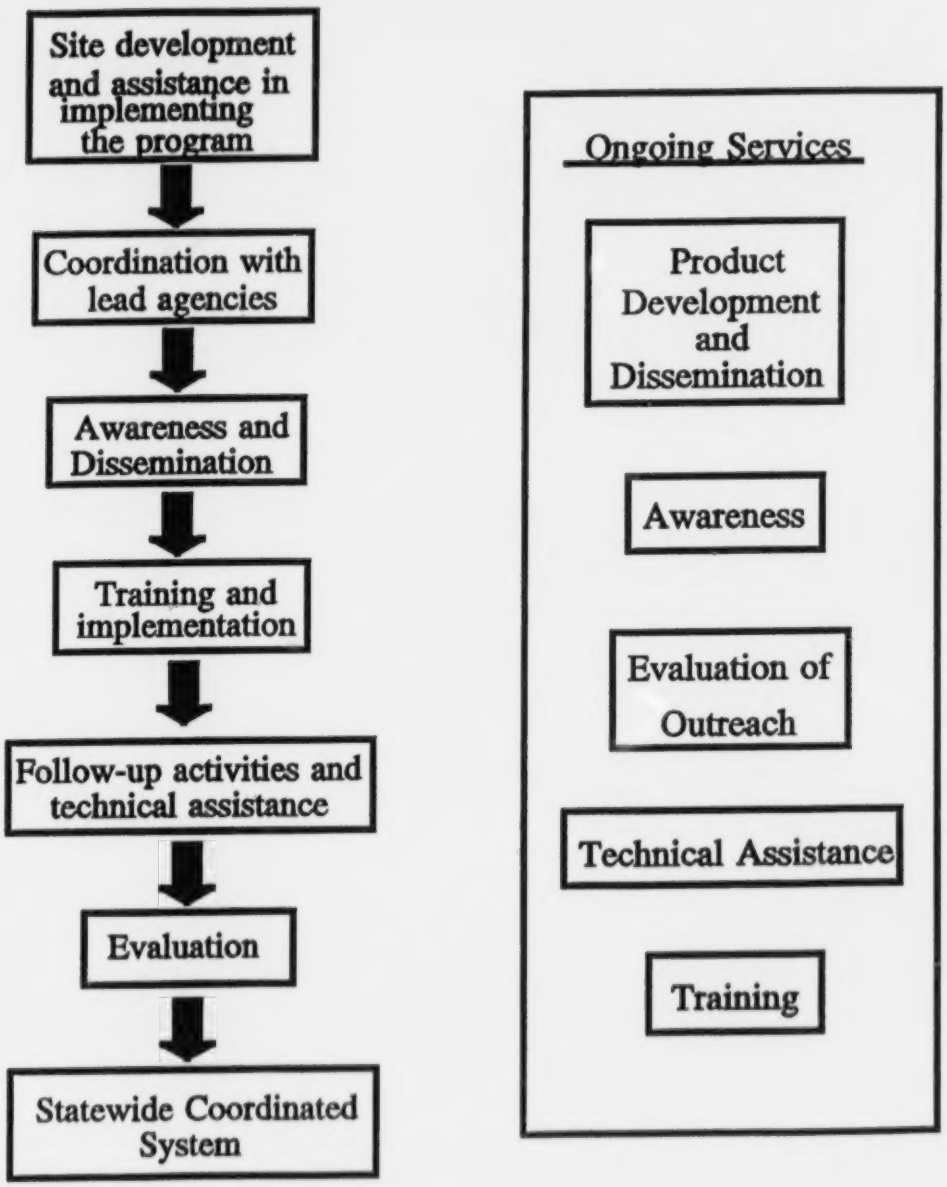
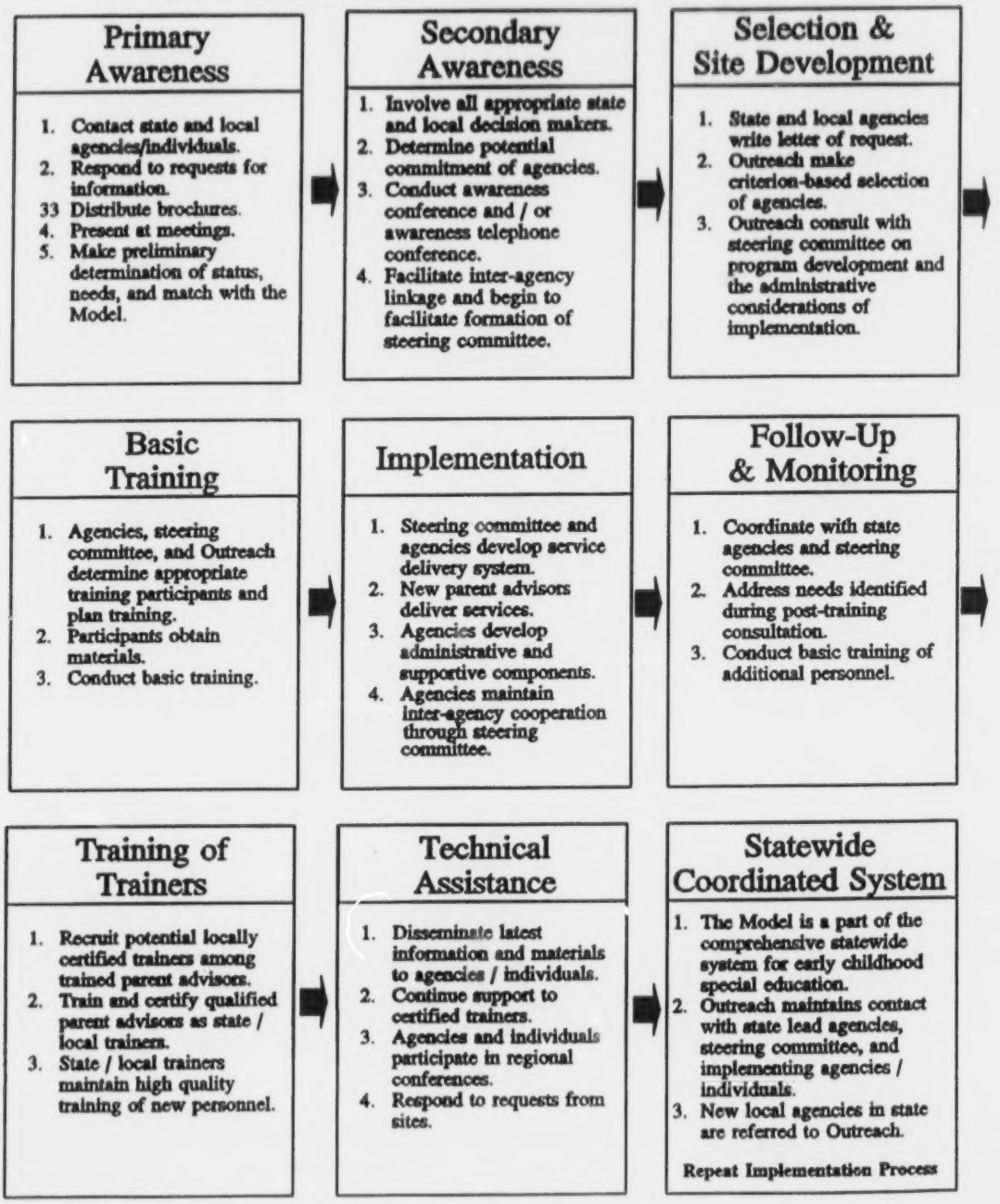


Figure 3

# The Implementation Process


Primary Awareness
1. Contact state and local agencies/individuals.
2. Respond to requests for information.
33 Distribute brochures.
4. Present at meetings.
5. Make preliminary determination of status, needs, and match with the Model.
Secondary Awareness
1. Involve all appropriate state and local decision makers.
2. Determine potential commitment of agencies.
3. Conduct awareness conference and / or awareness telephone conference.
4. Facilitate inter-agency linkage and begin to facilitate formation of steering committee.
Selection & Site Development
1. State and local agencies write letter of request.
2. Outreach make criterion-based selection of agencies.
3. Outreach consult with steering committee on program development and the administrative considerations of implementation.
Basic Training
1. Agencies, steering committee, and Outreach determine appropriate training participants and plan training.
2. Participants obtain materials.
3. Conduct basic training.
Implementation
1. Steering committee and agencies develop service delivery system.
2. New parent advisors deliver services.
3. Agencies develop administrative and supportive components.
4. Agencies maintain inter-agency cooperation through steering committee.
Follow-Up & Monitoring
1. Coordinate with state agencies and steering committee.
2. Address needs identified during post-training consultation.
3. Conduct basic training of additional personnel.
Training of Trainers
1. Recruit potential locally certified trainers among trained parent advisors.
2. Train and certify qualified parent advisors as state / local trainers.
3. State / local trainers maintain high quality training of new personnel.
Technical Assistance
1. Disseminate latest information and materials to agencies / individuals.
2. Continue support to certified trainers.
3. Agencies and individuals participate in regional conferences.
4. Respond to requests from sites.
Statewide Coordinated System
1. The Model is a part of the comprehensive statewide system for early childhood special education.
2. Outreach maintains contact with state lead agencies, steering committee, and implementing agencies / individuals.
3. New local agencies in state are referred to Outreach.
Repeat Implementation Process

## VII. Methodological/Logistical Problems And How They Were Solved

The project faced challenges in two main areas during the grant period: (a) a change in the needs of states, agencies, and training participants and (b) a need to maintain closer contact with the agencies and individuals who had received training and assistance in past years. These challenges, and the response by INSITE Outreach, are described below.

Challenge #1: The Change in Outreach Needs

When INSITE was first providing outreach training and assistance, the recipient agencies and individuals were those specifically serving children with sensory impairments or multiple disabilities in special programs. Since these agency personnel for the most part had a specialized educational background, training, and work experience with this population, INSITE training had been designed to build upon this existing knowledge and expertise. Traditionally, it consisted of two 3-day workshops, with 6 to 8 weeks in between.

With the advent of P.L. 99-457 and P.L. 102-119, children with low-incidence disabilities such as multidisability sensory impairments are now also beginning to be served within early intervention/early childhood programs for all infants, toddlers, and preschoolers with disabilities. In addition, states are expected to maintain more coordinated statewide services to children in the birth to 5 age range. The changes in service setting and state needs have opened a new arena and demand for INSITE Outreach services.

When the INSITE service model is delivered through local school districts and early intervention agencies, the personnel who deliver it often have not been trained to serve children with low-incidence disabilities such as sensory impairment with additional disabilities. Instead, they have generally received cross-categorical training, and may never have worked with a child with sensory impairment. The need for training to help prepare these personnel to effectively serve children with specialized needs has become acute.

On the other hand, in other locations or training situations, the participants may all be highly experienced and trained in specialized areas, but in different disabilities. There may be three or four subgroups in the workshop each needing a different set of information and skills.

Another problem encountered in facilitating the training is that often only one or two persons from an entire agency serve children with multiple disabilities and sensory impairment.

In addition, most early interventionists who are working with these children and need the specific training offered through INSITE are generally scattered through several agencies over large geographic areas. Except for the larger metropolitan areas, there are usually only a few children with sensory impairments with additional disabilities in each local early childhood or parent-infant program. Therefore, INSITE cannot expect to have all the participants in a workshop coming from the same agency to have training needs in common.

During the three years of this Outreach grant period, Project INSITE Outreach addressed these concerns by developing an awareness and training format designed to be flexible in meeting a variety of needs. In responding to today's demand for coordinated statewide services and for systemic change, INSITE Outreach conducts all awareness, dissemination, planning, training, and technical assistance through close cooperation with state education coordinators, Part H and Section 619 coordinators, and other lead agencies for services to children ages birth to 5 and their families.

Training is now offered in two formats, on-site and home-study, both designed to be individualized to participant needs. In the on-site training format, the first 3-day workshop is devoted to an overview of the INSITE model and resource manual, and a demonstration of how to assess a child initially for planning. Participants choose from a selection of assignments one that they will complete between workshops. They also choose which of the aspects of the model they would like to have covered in depth at the second workshop. There is a possibility of holding two concurrent sessions at the second workshop if the group is divided on needs. There is also a possibility that a full three days will not be used for the second workshop, if the participants do not feel a need for in-depth coverage of many of the topics. Also, trainers make use of the specialized expertise in each training group by inviting participants to assist in presentation in their specialty areas.

In the home-study format, the participants choose and complete one assignment before coming to the first 1 1/2 day workshop, which provides an overview of the program and an introduction to some of the program topics. Next, they choose and complete five additional home-study assignments. At the second 1 1/2 day workshop, they are introduced to other program topics and complete a final application exercise. See Appendix E for an INSITE training format overview.

This new approach to training and coordination has several benefits:

1. INSITE training may be adjusted and tuned in a great number of ways to meet the needs of each group of trainees. The expertise and knowledge of participants is acknowledged and utilized. Participants become more aware of the resources they have in their own local area.

2. The home assignments give participants a chance to become involved and get hands-on experience with INSITE. This contributes to a deeper understanding by the end of the training period.

3. Greater involvement by state agencies can help fill states' needs for a more coordinated approach to early intervention. INSITE provides a crucial piece in the states' provision of services to the birth-to-5 age group in fulfillment of requirements under Parts H and B of the Individuals with Disabilities Education Act.

For each of the sites which have received training during the reporting period, INSITE staff and trainers have consulted with the local coordinators before and after training in order to ensure continuity of implementation. Through the development of a central contact, either in the form of a state-level steering committee or through key agencies, the project has been able to further state-wide implementation by utilizing these committees to ensure that qualified personnel are selected for basic training and as state and local trainers.

Challenge #2: The Need to Maintain Closer Contact with Previously-Trained Agencies and Individuals

INSITE Outreach has conducted a survey of sites every year to update records and determine the yearly impact of INSITE. Outreach staff knew, however, that more information was needed about INSITE user agencies and individuals if appropriate technical assistance was to be delivered.

Therefore, during the first year and one-half of the Outreach project, a comprehensive survey of replication sites was conducted nationwide. There were two purposes: one was to determine the status of programming in these agencies. The second purpose was to determine what the agencies perceived as their greatest needs for ongoing technical assistance from the Outreach project.

The response indicated that the agencies were continuing to use INSITE programming and materials and were reading and using the newsletters and other mailings. They wanted to

continue receiving information and materials, and in addition, they wanted more opportunities for update training as well as certification of experienced parent advisors as trainers in the local areas.

In the area of need for and interest in technical assistance, the most frequently requested categories on the survey were (1) regional conferences and (2) administrators' sessions at regional conferences.

During the remainder of the grant period, INSITE Outreach joined with SKI-HI Outreach, another EEPCD project, to sponsor regional conferences. Conferences held during this period included the Western Regional SKI-HI/INSITE Conference, Durango, Colorado, August 4-6, 1993, the Southeastern Regional SKI-HI/INSITE Conference, St. Louis Missouri, June 16-18, 1994, the Northeast Central SKI-HI/INSITE Conference, Flint, Michigan, June 23-24, 1994, and the Northwest Central SKI-HI/INSITE Conference, Sioux Falls, South Dakota, July 13-15, 1994.

The goals that were accomplished through these conferences were (1) to bring SKI-HI and INSITE users together to share and gain new knowledge, (2) to establish closer contact between Outreach Project and these users, and (3) to encourage these regions to continue holding periodic regional conferences on their own. Additionally, INSITE Outreach is contributing staff consultative time and financial support to the groups who have taken on the responsibility of planning future conferences, while the SKI-HI Institute remains committed to sending one or more staff members to future conferences.

Evaluations and comments from all the regions continue to indicate that regional conferences are an excellent way to provide needed assistance and information as well as keep channels of communication open among INSITE users and between users and the SKI-HI Institute.

## VIII. Evaluation Findings

### A. Impact on Children and Families

Project INSITE was approved by the Program Effectiveness Panel of the National Diffusion Network in March 1989 as having provided "convincing evidence of the effectiveness of your program." This approval was based on data collected on children and families served by INSITE in 10 states from 1982 to 1988. Data from the validation study are summarized below. Data from the most recently reported data years, 1991-92, 1992-1993, and 1993-1994 are also summarized below. These data show that developmental claims during the first six years of INSITE still hold true. A copy of the 1991-92, 1992-93, and 1993-94 Annual Data Reports are in Appendix F.

The Callier-Azusa Scale is administered to INSITE children annually on a pre/post basis. This test is designed for children at lower developmental levels (e.g., children with deaf-blindness or multiple disabilities). The Callier-Azusa Scale is composed of 18 subscales which are organized according to the following five developmental areas: motor, perception, daily living, cognition/communication/language, and socialization. In 87% of actual versus predicted post-test score comparisons from 1982-1988, INSITE children scored higher at post-test time than what was predicted. Average annual post-test scores reveal that INSITE children score higher in all but one developmental area than would be expected due to maturation alone. Test scores were transformed to Intervention Efficiency Indices (Bagnato and Neisworth, 1980), and compared to pre-test developmental rates. These transformations yielded Proportional Change Indices (PCIs) which compared rates of development during intervention to rates of development at pre-test. All PCIs (100%) showed accelerated rates of development for the children during their INSITE programming.

INSITE programming continues to yield these positive results. In all data years 1991-92, 1992-1993, and 1993-1994 Callier-Azusa scores from INSITE children in reporting replication sites (1991-92 N=52 children, 1992-93 n=81 children, & 1993-94 N=24 children) were gathered and analyzed. For the 1991-92 reporting period, in all but one of the five developmental areas tested by the Callier-Azusa Scale, the actual mean post-treatment values not only showed improvement over pre-treatment values, but exceeded the predicted values. For

the 1992-93 reporting period, in all but two of the five developmental areas tested by the Callier-Azusa Scale, the actual mean post-treatment values not only showed improvement over pre-treatment values, but exceeded the predicted values. For the 1993-94 reporting period, in all but two of the five developmental areas tested by the Callier-Azusa Scale, the actual mean post-treatment values not only showed improvement over pre-treatment values, but exceeded the predicted values. These data indicate that INSITE children continue to score higher at post-test time than would be expected due to maturation alone.

To test rate of growth during intervention, PCIs were derived from the 1991-92, 1992-1993, and 1993-94 Callier-Azusa scores. In all developmental areas, the mean PCIs ranged from 1.0 to 2.5, with the mean range for 1991-92 from 1.3 for daily living to 2.4 for cognition, communication, and language; the mean range 1992-93 from 1.0 for motor development to 1.9 social development; and the mean range 1993-94 from 1.4 for perceptual development to 2.0 for cognition, communication, and language. Data from all three years of this training period indicate that the average INSITE child shows accelerated growth during INSITE programming in all developmental areas.

For the 1989 validation study, in order to determine how many INSITE "graduates" remain in the home versus "graduates" who were institutionalized, a survey was sent to INSITE program supervisors to determine current placement of INSITE graduates. Surveys from 10 states were received which included information on 853 graduates. The results showed that 99.7% of the INSITE graduates in this study were currently living in their homes while 0.3% were institutionalized. Of the 850 children living in their homes, all but 1.3% were receiving other services such as school or center-based services.

In parent skill acquisition during the years of 1986 to 1988, the typical INSITE parent acquired many new skills during an average time interval of 7.8 months. For example, parents learned an average of 14 new communication skills, which represents almost half of the total number of communication skills in the INSITE Program. All gains in skills acquisition in all curricular areas were statistically significant at the .05 level.

Seventy-one parents from eight states completed a parent perception scale. INSITE parents perceived significant improvement in their abilities to manage their child's disabilities and promote their child's development as a result of their participation in INSITE. Hundreds

of solicited and unsolicited letters from INSITE parents throughout the country further support the claim that INSITE programming is extremely important to them in meeting their child's needs and their own needs, especially in the area of emotional adjustment.

INSITE data demonstrate the effectiveness of the procedures and materials used to intervene and provide meaningful assistance to parents and families of children with MDSI. As children begin to show progress in attaining higher developmental milestones, parents are encouraged and their ability to parent their child is enhanced. The resulting increase in confidence these parents gain also enables parents to become truly effective advocates for their children who are MDSI.

**B. Evaluations of Outreach Activities**

Evaluations of outreach activities have been ongoing throughout this grant period. Evaluation data on awareness conferences, INSITE Basic training, workshops for new local trainers, technical assistance activities, and regional workshops are available upon request.

## IX. Project Impact

### A. State-of-the-Art Materials

The INSITE Project has developed, produced, and revised a variety of materials for use in training early intervention/childhood professionals in working with infants, toddlers, and preschoolers with sensory impairments and additional disabilities and their families. These materials have been distributed by the INSITE Project at the SKI-HI Institute and HOPE, Inc. in Logan, Utah. Below is a list of INSITE materials currently available. A full description of the listed materials is available upon request:

**Printed Material**

1. INSITE Curriculum, 2nd Edition, two volumes
2. INSITE Topic Summary and Challenge Sheet Pads
3. INSITE Developmental Checklist - Instruction Manual
4. INSITE Developmental Checklist 0-2 Short Form
5. INSITE Developmental Checklist 0-6 Long Form

**Videotapes**

1. Assisting Parents Through the Mourning Process
2. I Introduction to Tactile Communication for children Who Are Deaf-Blind
   II Using Tactile Signals and Cues With Children Who Are Deaf Blind (5 videotapes)
   III A Coactive Sign System for Children Who Are Deaf-Blind (9 videotapes)
   IV Using Tactile Interactive Conversational Signing With Individuals Who Are Deaf Blind (5 videotapes)
3. Overview of the INSITE Model
4. What Is a Parent Advisor?
5. Children With Motor Impairments (2 videotapes)
6. INSITE Home Visit
7. How Do We See?
8. Family Focused Interview (videotape and workbook)

**Monograph Series**

1. Monograph #6: Parent Advising; Personal Experiences and Reactions
2. Monograph #7: Working With Families of Young Children With Special Health Care Needs

**SKI-HI Materials in Spanish**

1. Parent Notebook
2. Developmental History Form

The INSITE Outreach Project is a growing, changing model that is concerned with services provided to families of young children with sensory impairments and additional disabilities. A constant effort is maintained to ensure that the model represents the latest research and best practice in the field.

Project INSITE also contributes to the SKI-HI Institute newsletter that goes out to VIISA, INSITE, and SKI-HI users throughout the country three times a year. The project also contributes to the biannual ''Trainer's Tidings'' that is mailed to all local and national VIISA, INSITE, and SKI-HI trainers/instructors across the country.

## B. Summary of INSITE Activities

Project INSITE assists with the annual survey that goes to replication sites and programs around the country. That information, along with data kept at the project office provide the information needed for the INSITE fact sheet which follows. These reflect the impact INSITE has had for the grant period 10-01-92 to 9-30-95 and for the extension period from 10-01-95 to 3-31-95.

Summary of Impact of INSITE Activities 1992-1996

| | National |
|---|---|
| Dissemination of information to state agencies | 50 |
| Number of INSITE courses, taught in states | 11 |
| Number of Children estimated to benefit from training participants received from the INSITE courses | 1380 |
| Consultation provided to sites | 26 |
| Instructor workshops to certify new state trainers | 3 |
| Number of new state instructors certified and receiving training materials | 23 |
| National staff meetings for update, retraining, and revision of training packages | 1 |
| Number of national INSITE instructors | 12 |

## X. Future Activities

### A. Training, Impact on Professionals, Programs, and Families, Assistance to Sites

Project INSITE wrote a grant application for a new 3-year period (1995-98) through OSEP-EEPCD and has been funded to continue as an Outreach project with new states and programs around the country as well as to provide continued assistance to established sites. Continuation funding will also enable the project to develop new training and curricular material as needed.

Through this INSITE Outreach grant, the following impact is expected.

1. At least 100 professionals in four states will receive training in the INSITE Model during the Project. Each trained professional is estimated to serve a minimum of two children annually with the INSITE material.

2. INSITE will continue to grow and expand in most of states where training has taken place. An additional 1500 families and 700 professionals in continuing INSITE agencies will receive ongoing assistance.

3. An estimated 30 new state instructors will be trained through the state instructor training workshops conducted annually.

4. The Project will participate in regional INSITE/SKI-HI/VIISA workshops in several locations around the country.

5. Technical assistance can continue to be provided to the existing sites.

### B. New Products and Materials

Through this new grant, the following materials are being developed:

1. A new edition of the INSITE Resource Manual, the central resource to INSITE users.

2. Updated course manuals, videoclips, and home study manuals for use in INSITE courses.

3. Updated management manuals.

4. Three yearly newsletters sent to over 2,000 professionals in the VIISA/SKI-HI/INSITE network.

5. Two yearly Trainers' Tidings distributed to all national and local trainers and instructors.

6. Update information for instructors and trainees on research and best practice approaches to use with this population of young children with sensory impairments with additional disabilities.

## XI. Assurance Statement

INSITE confirms that the full text of this report is being sent to ERIC and that copies of the title page, overview, and summary have been sent to the others addressed on the attached sheet.

# APPENDIXES

# APPENDIX A

Sample Newsletter

SKI-HI INSTITUTE

# NEWSLETTER

SKI-HI INSTITUTE
Utah State University
809 North 800 East
Logan, UT 84322-1900
(801) 752-4601

Fall Issue
Volume XIX
October 1995

## THINK HOW FAR WE'VE COME!

**BY**
**DOROTHY JOHNSON**

Since the SKI-HI Institute Newsletter will change to a combined format with the AAHBEI Newsletter with the next issue, the SKI-HI staff thought it would be fun to share some reminiscences of the two earliest Institute models, SKI-HI and INSITE, with you.

We recently reestablished contact with one of the first families ever in the Utah SKI-HI Parent-Infant Program during the developmental years. They are the Casperson family, and it was a great pleasure to talk with Julie and her parents now that Julie has grown up. We also asked Sue Watkins, who was then their parent advisor, to share her memories. An article about those conversations is included in this issue. As many of our readers know, SKI-HI got its start as a demonstration model in Utah back in 1971. During those early years, we were lucky enough to have Tom Clark as Director, Skip Reese as Coordinator, and Sue Watkins as Audiologist and Parent Advisor, with the support of Robert Tegeder as Superintendent of the parent agency, the Utah Schools for the Deaf and the Blind. This team, along with the early parent advisors, wrote and field tested the first SKI-HI Manual between 1971 and 1975. The fruit of their dedication and commitment has been years of growth, joy, and excellence of service to the families of children who are deaf and hard of hearing across the United States and in foreign lands.

INSITE was created in 1981 and began its life at the Utah Schools for the Deaf and the Blind as well. Tom Clark as Director and Bess Morgan as Coordinator took INSITE through its development years. In this issue, Bess tells that story in a wonderful way. INSITE has also spread throughout the United States and is in much demand by those who work with the families of young children who are sensory impaired with additional disabilities. Enjoy!

## *"We Call It Intervention, But It's Really Another Form Of Love"*

***by Barbara Glover***

This is how Glen Casperson describes the SKI-HI intervention that his family received after his daughter Julie was diagnosed with a hearing loss. Julie Casperson is the second of four daughters of Becky and Glen Casperson. Julie was two years old when her parents began to think that perhaps she was not hearing, that maybe she was missing out on some of the things that were going on around her. At this point in time Becky felt frustrated. "We didn't know what to do or where to go or who to see." Whenever Becky and Glen took Julie to the pediatrician he would say that she was quick to respond and track objects. He really couldn't see anything that would indicate that Julie had a hearing loss. At 2 1/2 after further testing it was confirmed that Julie did have a hearing loss and she was sent home from the doctor's office with hearing aids.

Glen described this as a "shock." "We didn't know what we would be faced with. It was all unknown." Becky

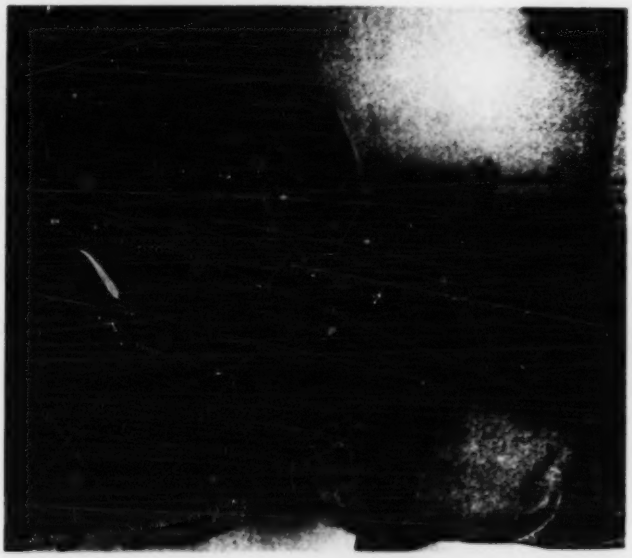
***Julie Casperson***
***— Then —***

related that Julie did not like to wear the hearing aids at first. "We would find them downstairs or in the grass. One time Glen ran over them with the lawn mower." SKI-HI Early Home Intervention was very comfortable for the Caspersons as the whole family participated together. Glen remembers, "We learned together how to help Julie learn to use the hearing aids and learn to speak." As Becky says, "Our parent advisor was such a blessing in our lives! We needed that experience...I don't know what we would have done without it."

Julie is now a very capable young woman and a new bride. She communicates very well with friends and family. The Caspersons are a great example of love, encouragement, and knowing that there is no limit to what you can do.♦

## *Memories Of Early Days With The Caspersons*
***by Sue Watkins***

It was always a real joy to go to the Casperson home in Brigham City. I looked forward to visiting this family with great enthusiasm. There were several reasons this was so. First, both Glen and Becky were very dedicated and committed to their children and to Julie. They wanted what was best for Julie and were diligent in discovering and learning ways to meet her needs and maximize her potential. They were also such loving and caring parents and so supportive of each other and their children. Next, I'll just have to admit that Julie was (and definitely still is!) a real charmer! As a little girl, her cuteness, animation, gregariousness and charm were very apparent to everyone. She was always responsive to the home visit activities and approached almost everything she did in a spirit of fun. Another reason I so enjoyed visiting this family was because most of the time, all of the family members were there. It was very rewarding to work with the whole family and see their interest in and support of Julie and the SKI-HI Program in action.



***Julie Casperson***
***— Now —***

I remember many of the visits with satisfaction and fondness...but one visit in particular stands out in my mind. Julie's dad had just come home from duck hunting, and he was sort of flinging the carcasses in a pile in the garage. I will never forget Julie's big eyes getting bigger and bigger at the sight of this. Her dad (always looking for opportunities for language input, of course!) made a big deal out of the stacking process and then later about the pain each dead bird was feeling as he pulled the feathers out. Julie was very enthralled with all of this and learned an incredible amount of new language in a very short time including bleed,



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hurt, tug, tug harder, pinfeathers, big ow's, little ow's, and the like.

It was a real pleasure to serve the Casperson family and to see Julie's communication, language, and personality unfold and grow. Today, Julie is a very communicative, very charming, very lovely young woman whose family is very, very proud of her! ♦

## *The Early Years of INSITE*
### *by Elizabeth Morgan*

In the Summer of 1981, the INSITE model demonstration grant was funded as a combined effort of the Utah School for the Blind and the SKI-HI Institute at Utah State University. I was hired on as full-time coordinator of the grant. Other part-time staff members included nine parent advisors, two of whom are Susan Williams and Phyllis Snow, national trainers for INSITE Outreach; Tom Clark, director; Juanita Watts, psychologist; Pat Boyle, consulting physical therapist; Dr. Armstrong, ophthalmologist; and audiology staff at the Utah School for the Deaf.

INSITE's mission, in part, was to provide weekly home visit services to families of thirty children who lived in the rural areas of the state. The disabilities of these children ranged from total blindness or partial sight with no other impairments to children who were deaf-blind and sensory impaired with additional disabilities. Those of you familiar with the size of our western states can understand the distances that lay between these families and the main project office in the northern part of the state. So, the project recruited and began to train nine part-time parent advisors who lived in the rural communities of the state to work with these children and their families.

The parent advisors were brought in to the School for the Blind several times a year for staff meetings and training. As coordinator, I had weekly contact with them by phone and read and responded to monthly home visit reports. Then, several times a year, along with another staff member (e.g., the psychologist, the physical therapist), we traveled the state to visit each parent advisor and the children and families they served. I remember one fall, when we decided to do the eastern and central areas of the state in a two-week trip. When we arrived back home, we had covered 3,000 miles!

These were multipurpose trips with agendas that usually took us from morning till night. We visited homes; the preschool programs that some of our children were integrating into; conducted workshops for parents; visited health nurses; and provided some pediatric physical therapy consultation for families, sometimes in conjunction with a local therapist. Many of the first INSITE children had motor problems and there were few therapists in the rural areas of the state who had worked with these kinds of children before. The project's consulting therapist helped to provide some training to these local people on some of these trips. Sometimes, we had a few extra minutes to take a side trip into one of the many wonderful national parks of southern Utah (e.g., Bryce, Zion, Arches, Capitol Reef).

Another big task was to get pulled together on paper what it was that we were doing in homes with our first INSITE families. Tom Clark was always reminding me to work on this part of the INSITE project since the direct service part of the program was my first love. Little by little, the first set of INSITE resource manuals began to come together with the help of Pat, Juanita, the nine parent advisors, and other consultants.

Each summer, we would bring the parent advisors who were interested in curriculum writing together for a week in the dorms of the School for the Blind to work on the INSITE resource manuals. The walls of the room we worked in had chart paper with writing on it all over the place. One of those weeks, the maintenance staff forgot to turn the hot water back on for us since all the dorm students had gone home for the summer. So, we had to live with a week of cold showers. We were the only people in a large, empty, spooky dorm which used to be a sanitarium in the old days. It had an old morgue in the basement. For those of you who are newcomers to INSITE, the first set of manuals had four volumes, not the two that now exist as a result of revisions made in 1989.

The third year of the INSITE model demonstration grant was a very busy one, with several new things starting to take shape.

The first had to do with the "intervener concept." Both Tom Clark and I had the opportunity to visit Canada to learn more about their use of interveners with deaf-blind children and youth. We then had John McInnes, one of the key players from the Canadian program, come visit us in Utah. I remember that visit quite well, since I had just learned

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to drive a stick shift. I was given an old stick shift station wagon to pick Mr. McInnes up from the Salt Lake airport and I was very nervous about driving it. Sitting at a stop light in downtown Salt Lake, I put the car into reverse instead of forward when the light turned green, barely missing front ending the person behind me. Our guest offered to drive.

Following that visit, we obtained permission from our project officer in Washington, DC, to use some of the third year INSITE grant monies to train and put interveners into the homes of six young preschoolers who were deaf-blind in our Utah program. What we learned through this trial phase helped to form the base for a new intervener grant application the following year. Utah has continued to work with the intervener concept since the early years of INSITE through both federal and state monies.

In the winter of our third year, INSITE staff also wrote a state grant to pilot the use of teacher consultants for the blind and visually impaired to serve school-age children in the rural areas of the state. We had the backing of the special education directors in the rural school districts. Some of our INSITE children were moving into school-age programs and for their families, the only educational choice was to send them hundreds of miles away from home to the state school, or keep them in their local community with consultative services from a vision specialist 2-3 times a year. There were no trained vision teachers in the rural areas and no teacher training program for vision in the state at that time.

With the little bit of state funding we had, time from INSITE, and the time of another School for the Blind staff member, Dorothy Smith, we started the process of recruiting part-time regular or special education teachers in the rural areas of the state. We began to give them some training and supervision as they provided weekly services to students with partial sight in those rural communities of Utah. A year later, permanent state funding for this school-age outreach program was obtained from the legislature. This program has now grown to serve 147 children and youth with a full-time director and eleven teacher consultants, seven of whom have or are working on their vision certification through a special training program in the state.

Also, during that third year, with the help of our INSITE families and the Schools for the Deaf and the Blind, permanent state funding was obtained from the legislature to continue the services families in the rural areas had been receiving during the three year grant period. And towards the end of that third year, the INSITE outreach grant which we had written was approved for funding. This was to begin INSITE's ten-year history of outreach and training across the United States.

Over the past ten years, INSITE has provided training to hundreds of parent advisors who have used the information in the resource manuals with over 2,300 children and their families per year in 30 states across the country. INSITE has continued to produce new materials for use by parent advisors and state and local trainers. INSITE funded "out of hide" the writing of the VIISA resource manual. This made it possible to obtain funding for the VIISA model inservice training grant for preschoolers with vision impairments.

There is still much work for INSITE to accomplish, one of which is a much needed second revision of the resource manuals to be completed over the next few years. INSITE is also embarking on a new adventure, that of offering training through a combined onsite/home-study format that has already been successfully used by both the SKI-HI and VIISA projects. States will still have the option of using the six-day onsite format as well.

Let's all hope that our present Congress doesn't put an end to this project which has helped to bring about a great deal of good over the last 13 years. Long live INSITE!♦

# The Katie Beckett Waiver

## by Elizabeth Morgan

The Katie Beckett Waiver is a way to get Medicaid for a child when the parent's income is too high for them to qualify for Supplemental Security Income (SSI). To apply for the waiver, the parents must first apply for SSI and be turned down, then provide a copy of that rejection letter in their application to Medicaid.

Katie Beckett was a little girl in the 1980's who had many medical and physical complications. Her parents

wanted her to come home from the hospital to live with them. The family income was higher than social security allowed in determining SSI; however, the income was not nearly enough to cover all the medical and therapy bills. Eventually, a special Medicaid Waiver was granted so that Katie Beckett could live at home with her family. Since that time, the Katie Beckett Waiver has helped many children who would have been forced by Medicaid regulations to remain permanently in hospitals or institutions. Present welfare reform in Congress threatens to eliminate funding for this waiver.

The Katie Beckett Waiver is administered at the state level and is, therefore, only available to residents of the states that have adopted it. Most states have some form of the waiver and regulations are often complex and vary widely.

In general, the waiver may apply to a situation involving a child with a disability under the age of 18 for whom home care is appropriate and in which the child needs a level of care equivalent to that given in an institution. The cost of home care must be less than or equal to the cost of institutionalization. The waiver is also only available to children who would qualify for Medicaid should they be institutionalized. However, the child with the disability does not have to be in an institution to qualify for it.

This Medicaid waiver may help to pay for things such as doctor and hospital bills, medicines, therapy and adaptive equipment. Families with insurance may apply for the waiver, too.

If a family is interested in applying for the Katie Beckett waiver, they should contact the Medicaid office in their state. Since not all the Medicaid workers may know about the waiver, the parents may need to be persistent in their efforts. The application process is quite long (especially with the SSI part) and parents may need some encouragement along the way.

If their Medicaid application is denied and they think they qualify under the Katie Beckett Waiver, parents should then contact their local Protection and Advocacy office or the local legal services office for advice. For their local offices, they may contact the National Legal Aid and Defense Association, 1625 K St., NW, Ste. 800, (202) 452-0620 (voice), (202) 872-1031 (fax).◆

**'85 MIDDLE EAR MONOGRAPHS AVAILABLE**

**If you can use copies of the 1985 edition of the Middle Ear Monograph, you are welcome to them at no cost. The information is still very usable, but it was written to accompany the 1985 edition of the SKI-HI Manual. A new 1994 update is now in print to accompany the 1993 SKI-HI Manual.**

**Please contact Fran Payne at SKI-HI Institute, (801) 752-4601 (phone) or (801) 755-0317 (fax), soon if you would like some of these monographs.◆**

## NEW SKI-HI AND INSITE LOCAL TRAINERS

The SKI-HI Institute is pleased to announce the addition of 21 new SKI-HI and INSITE local trainers. Trainings were held in June in Des Moines, Iowa, and in Ogden, Utah.

*Back Row (L to R): Richard Miske, Lois Mahoney, Kathy Carter, Velda Hill, Jeanne Fowles, Marian Smout, Gay Teter, Barb Schneider.*
*Front Row (L to R): Kay Hansen, Joan Fargnoli, Lorie Ybarolla, Amy Bove, Nanette Serrano, Missing: Carol Winn.*

Thirteen Parent Advisors representing seven states attended the SKI-HI Training Workshop conducted by National Trainer and Institute staff member, Dorothy Johnson. The following people are welcomed into the SKI-HI family as qualified Local Trainers: Nanette Serrano (CT), Lorie Ybarrola (IA), Barb Schneider (IA), Richard Miske (IA), Joan Fargnoli (NY), Velda Hill (OK), Gay Teter (OK), Jeanne

Fowles (UT), Carol Winn (UT), Marian Smout (UT), Amy Bove (VT), Kathy Carter (WY), and Lois Mahoney (WY).

Eight Parent Advisors representing four states completed the INSITE Local Training Workshop conducted by National Trainer and Institute staff member, Elizabeth (Bess) Morgan. We welcome the following Parent Advisors into the INSITE family of Local Trainers: Donna Embree (LA), Diana Smith (LA), Amy Twetten (IA), Jan Lamm (IA), Donna Bachman (IA), Teresa Smith (OH), Emily Taylor-Snell (OH), and Jane Seaton (GA).

*Left to Right: Emily Taylor-Snell, Jan Lamm, Teresa Smith, Donna Embree, Donna Bachman, and Amy Twetten.*

Our congratulations are extended to these Parent Advisors who contributed many ideas with much enthusiasm to the trainings. We are pleased by the dedication to families and young children expressed by these new Local Trainers and wish them well as they begin training in their own states and local areas. We remind these new trainers that they need to contact the Institute prior to their first training to receive the required assistance from a National Trainer.♦

## CONFERENCE CALENDAR

**NATIONAL CONFERENCE FOR ACTIVE LEARNING FOR INFANT, PRESCHOOL, AND MULTI-IMPAIRED BLIND AND VISUALLY IMPAIRED CHILDREN: AN AMERICAN REVIEW** featuring speakers from across the U.S., November 13-17, 1995, Seattle Washington. Nationally recognized practitioners who have been instructed by Lilli Nielsen in her Active Learning Approach will share what they have been doing since her materials were introduced in the United States in 1991. Participants will have the opportunity to learn firsthand about innovative and unique growth environments, such as "The Little Room," "The Resonance Board," "The Bench," and other equipment. Registration fees are $300 for professionals and $200 for parents before October 6, 1995. Those interested should contact: Sherry Raynor, The Blind Children's Fund, 2875 Northwind Drive, Suite 211, East Lansing, MI 48823-5040, Tel: (517) 333-1725, Fax: (517) 333-1730; or Didi Goodrich, Resource Center, The Blind Children's Fund, 2971 53rd Street SE, Auburn, WA 98092-8310, Tel: (206) 735-6350. ♦

## NEW PRODUCTS

*Products listed in the SKI-HI Institute Newsletter do not imply endorsement by SKI-HI Institute. They are provided for informational purposes only.*

***Starting Points*** is an excellent new book available from the Blind Children's Center in Los Angeles on programming for children with multiple disabilities whose impairments include vision. Address/phone number of the center are 4120 Mara- thon Street, Los Angeles, CA 90029-0159, (213) 664-2153.

***Your Baby and You*** is a new 25-minute videotape and booklet for parents of infants who are premature. It is designed to help caregivers understand what various behaviors are communicating. For those of you familiar with Premie Potential, this is a nice replacement since that one is no longer available. Order this from Communication and Therapy Skill Builders, (602) 323-7500, in Tucson, AZ.

***The Hoyt-Akeson Selected Readings in Pediatric Ophthalmology*** is an excellent binder of research articles for medical and educational professionals working with infants and preschoolers with visual impairments. It is available for $67.50 from Blind Babies Foundation, Attn: Selected Readings, 1200 Gough Street, San Francisco, CA 94109. Call (415) 771-5464.

***Technology for Tots*** is an inexpensive booklet on using computers with preschool children who have visual impairments. It is available from The Lighthouse National Center for Vision and Child Development, 800 Second Avenue, New York, NY 10017. ♦

## NATIONAL TRAINING CALENDAR

### SKI-HI

**Iowa** January 11-12, 1996
Trainer: Tracy Duncan April 18-19, 1996

### INSITE

**Louisiana** August 3-5, 1995
Trainers: Mary Franks/Donna Embree/ Diana Smith October 19-21, 1995
**Alaska** October 15, 1995
Trainer: Tanni Anthony February 11-13, 1996

### VIISA

**Pennsylvania - West** in Gibsonia September 15-16, 1995
Course on Infants and Toddlers December 1-2, 1995
Instructors: Team of State Instructors

**Pennsylvania - East** in King of Prussia September 29-30, 1995
Course on Infants and Toddlers December 8-9, 1995
Instructors: Team of State Instructors

**West Virginia** - Onsite #1 October 6-7, 1995
Course on Infants and Toddlers
Instructors: Team of State Instructors with Lois Hammett

**Florida** October 19-20, 1995
Planning and Training with State Training Team
Instructor: Debbie Gleason

**Florida** December, 1995
Course on Infants and Toddlers
Instructor: State Training Team

**South Carolina** October - December, 1995
Course on Preschoolers
Instructors: State Training Team and Lois Hammett
**Missouri** Fall, 1995
Course on Preschoolers
Instructors: State Training Team

Follow-up sessions for VIISA participants in Louisiana and Ohio are also in the planning stages.

## SKI-HI INSTITUTE STAFF

| | |
|---|---|
| ***Don Barringer*** | **Institute Director** |
| ***Linda Alsop*** | **Intervener** and **TRISH** Director |
| ***Elaine Brandenburg*** | Secretary/Receptionist |
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| ***Barbara Glover*** | **NDN** Coordinator |
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| ***Pat Jones*** | **AAHBEI** Director/Secretary |
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| ***Gary Mauk*** | Research Associate |
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## SKI-HI INSTITUTE ADDRESS CARD

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**INSITE** _____
**Year trained** _____

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**Do you wish to continue to receive the SKI-HI Institute Newsletter? Yes** _____ **No** _____

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**Department of Communicative Disorders**
**Utah State University**
**Logan, Utah 84322-1900**

**ADDRESS CORRECTION REQUESTED**



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# APPENDIX B

Family Resource Notebook:

Cover Page & Table of Contents

# FAMILY RESOURCE BOOK


**Editors:** Mary Ann Parlin
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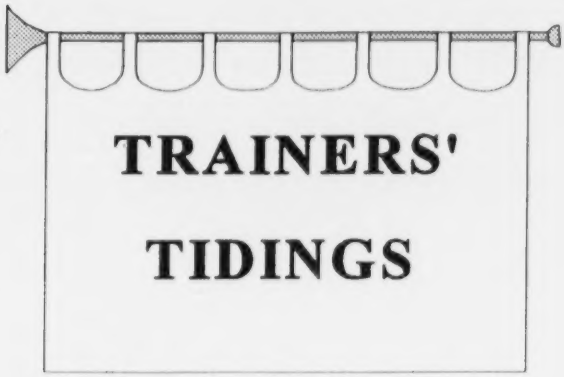
# APPENDIX C

Trainers' Tidings: Table of Contents



# TRAINERS' TIDINGS

*A Newsletter By and For SKI-HI Institute Trainers and Instructors*

*Volume 6, Issue 1* *November, 1995*

## Greetings!

*The purpose of this newsletter is to keep you informed about training activities of the SKI-HI Institute, as well as to share materials and ideas that can be used in training.*

*This issue contains:*

**SKI-HI INSTITUTE NEWS**
- Revisions to Trainers' Manuals: VIISA & INSITE
- Celebrate with Three National Trainers!

**TRAINING NEWS**
- Surrounded by Mountains, Spirited New SKI-HI Trainers Teach Each Other
- Eight New INSITE Parent Advisors
- National Training Calendar

**TRAINING IDEAS AND RESOURCES**
- Music Game or Quiz for INSITE
- A Learning Activity for Topic: Roles and Characteristics of the Parent Advisor
- Tips from SKI-HI Trainers
- Tips for Instructors

**NATIONAL AND LOCAL TRAINERS**

**NEW RESOURCE ARTICLES AND MATERIALS**
- The Katie Beckett Waiver
- An Overview of Adult Learning Principles
- New Products
- And Then Some
- Attitude

**FORMS EVERY TRAINER NEEDS**
- Training Reports and Attendance Lists: Essential to Send to SKI-HI Institute

**CONFERENCE CALENDAR**
- Zero to Three's 10th National Training Institute
- National Conference for Active Learning for Infant, Preschool, and Multi-Impaired Blind and Visually Impaired Children: An American Review

*Trainers' Tidings*, published twice yearly by the SKI-HI Outreach Staff

# APPENDIX D

The Insite Model

Overview

Volume 1: Table of Contents

Volume 2: Table of Contents

Sample Agenda

# OVERVIEW OF THE INSITE PROGRAM

**Rationale**

The INSITE Program offers home-based family support for families with infants, toddlers, and preschoolers, aged birth to five, who are sensory impaired with additional disabilities. The INSITE Program originated from a need to provide home-based programming for young children who needed more services than existing programs for the deaf, hard of hearing, blind, or visually impaired had to offer. The rationale for early home intervention for families of these young children is strong. Sensory impairments with additional disabilities (that is deaf-blindness, deafness with other involvements, or blindness with other involvements) are very traumatic to families and individuals. The developmental effects of combined sensory impairment are staggering. That which is not systematically taught, often through touch, will not be learned. INSITE programming is extremely important to families as they struggle to meet their needs and the needs of their child who is sensory impaired with additional disabilities.

Families share common elements of affiliation and caring for their members, but they differ dramatically in overall structure, membership characteristics and the impact that social-historical events have had on their lives. Changing family structures and systems have expanded INSITE service and delivery systems to foster and support the family's ability to achieve collective goals and perform the tasks of daily family living.

It is important to view young children who are sensory impaired with additional disabilities as part of interactive family systems with family members as prime facilitators. In the home setting, intervention can best be tailored to the family, the individual child, and unique family systems. Pressure on the family is intense due to such factors as medical intervention, infant unresponsiveness, lack of sensitivity by professionals, and extremely high child-care demands. With support and guidance, the family members can become prime facilitators of development for the young child.

**Description**

INSITE home intervention services are delivered to the family in the home and/or to other alternate locations with alternate caregivers by a professional, called a parent advisor. The parent advisor and family form a partnership with the goal of optimizing the child's development and enhancing the family's knowledge and skills. The parent advisor usually visits the home on a weekly basis to offer support, information, and demonstrate skills as requested by the family. The INSITE Program provides resources for the family and parent advisor in close coordination with the hearing specialist, vision specialist, physical therapist, occupational therapist, or other professionals that may be involved with the child.

The parent advisor also helps the family work towards transdisciplinary coordination among all professionals and agencies serving the family. A transdisciplinary approach is a very effective way to plan and implement early intervention services for children who are sensory impaired with additional disabilities as it involves a team working together to assess, plan, and implement programming that will meet the total needs of the family and child. The parents and parent advisor assess, write, and review the Individualized Family Service Plan (IFSP), and carry out and monitor the goal oriented activities. Parents are directly involved in assessing their child's and family's needs, developing family or child goals, and selecting experiences and activities in which to practice new skills with their child.

Through the IFSP process, INSITE program, and other community resources the family, parent advisor, and other team members working in partnership can determine the child's developmental needs and address those needs through the INSITE resources as follows:

Communication Development: The INSITE Program includes information and skills in communication interaction and methodology to assist the family in establishing a communicative relationship that includes and involves the child.

Hearing and Auditory Development: The INSITE Program offers information for families on the treatment of hearing disorders, which includes fitting and management of

hearing aids and information on ways to promote the development of the child's residual hearing.

Vision Development: The INSITE Program provides families with ways to help the child learn to better use the vision he or she has and ways of helping the child compensate for loss of vision.

Cognition Development: The INSITE Program assists families in promoting early skills in the child including object exploration, gestural imitation, means-end, causality, object permanence, and spatial relations.

Motor Development: The INSITE Program provides parents with information and techniques for understanding posture and movement and for helping the child make the best use of his or her motor capacity.

Developmental Resources: The INSITE Program has designed resources to use in gross motor, fine motor, self-help, and social-emotional development for young children who are sensory impaired with additional disabilities. The team combines these resources in an individualized way that best develops the whole child and meets the family's priorities.

The INSITE Program has developed and produced a variety of materials for use in home intervention with infants, toddlers, and preschoolers who are sensory impaired with additional disabilities and their families. INSITE provides instructional, management, testing and training materials. These materials are essential to successful early home-based programming.

**Evidence of Effectiveness**

To evaluate the effect of the INSITE program on child progress, site personnel are trained in the INSITE methods of performing child assessment and data collection and submitting data on child progress. Sites are encouraged to submit their data once a year to the national INSITE data bank.

Project INSITE was developed through a three year federal model demonstration grant from 1981 to 1983 in Utah. In 1984, INSITE became funded as a federal outreach model and has been replicated in about 24 states since 1984. In March of 1989, INSITE was approved by the Program Effectiveness Panel of the National Diffusion Network, as having provided "convincing evidence of the effectiveness of your program." This approval was based on data collected on children and families served by INSITE in 10 states from 1982 to 1988. Data from the validation study are summarized below. Data from the most recently reported data year, 1993-94, are also summarized below. These data show that the developmental claims during the first six years of INSITE still hold true.

The Callier-Azusa Scale is administered to INSITE children annually on a pre and post basis. This test is designed for children at lower developmental levels (e.g., children with deaf-blindness or multiple disabilities). The Callier-Azusa Scale is composed of 18 subscales that are organized according to the following five developmental areas: motor, perception, daily living, cognition/communication/language, and socialization. In 87% of actual versus predicted post-test score comparisons from 1982-1988, INSITE children scored higher at post-test time than was predicted. Average annual post-test scores revealed that INSITE children score higher in all but one developmental area than what would be expected due to maturation alone. Test scores were transformed to Intervention Efficiency Indices (Bagnato & Neisworth, 1980), and compared to pre-test developmental rates. These transformations yielded Proportional Change Indices (PCIs) which compared rates of development during intervention to rates of development at pre-test. PCIs of INSITE children from 1982-1988 were computed: all PCIs (100%) showed accelerated rates of development for the children during their INSITE programming.

INSITE programming continues to yield these positive results. In the most recently reported data year 1993-94, Callier-Azusa scores from INSITE children in 5 replication sites were gathered and analyzed. In all but one of the five developmental areas tested by the scale, the actual mean post-treatment values not only showed improvement over pre-treatment values,

but exceeded the predicted values. These data indicate that INSITE children continue to score higher at post-test time than would be expected due to maturation alone.

To test rate of growth during intervention, PCIs were derived from the 1993-94 Callier-Azusa scores. In all developmental areas, the mean PCIs were above 1.0, ranging from 1.4 for social development to 2.4 for daily living. Thus, it can be stated that the average INSITE child shows accelerated growth during INSITE programming in all developmental areas. Recent assessment data show that our average child improved in all areas of the Callier-Azusa Scale and that all but one post-test value exceeded what would have been expected in the absence of treatment. In general, the average child's overall rate of development improved during INSITE intervention.

INSITE data demonstrate the effectiveness of the procedures and materials used to intervene and provide meaningful assistance to parents and families of children who are sensory impaired with additional disabilities. As children begin to show progress in attaining higher developmental milestones, parents are encouraged and fortified in their ability to parent their child. This confidence is magnified and is manifested in that parents become truly effective advocates for their children.

**INSITE Basic Training**

INSITE Basic Training prepares professionals to be parent advisors helping families acquire information, skills, and support in facilitating the development of their young children who have sensory impairments combined with other disabilities. It includes a comprehensive overview of the rationale and organization of the INSITE Model, including early identification, administration, and supportive service components.

The majority of the workshop time is devoted to training in the direct services to families. Participants discuss application of the principles of early home intervention. They become familiar with the INSITE resource manual which contains information and activities for families on early communication, audition, vision, cognition, motor impairments, and the

development of auditory and visual skills. They learn the INSITE approach to information gathering, child assessment and program planning needed for developing the IFSP.

The training is presented by two certified INSITE trainers who combine multi-media presentations, large and small group discussions, role-playing, problem-solving, and hands-on experiences. The training is designed for the service delivery professional who will be making weekly visits to the families.

The basic INSITE training is six days in length, in a two-workshop series with an assignment between both workshops. (See diagram of INSITE training formats on the next page.) Since this format is not practical for all agencies, the SKI-HI Institute can provide alternatives based on need and feasibility. For example, INSITE is now working on a training format that will involve four days of onsite training with six home study assignments spread out over a period of 10-12 weeks.

The desired outcome of INSITE training is to enable the families of young children with sensory impairments and other disabilities to receive high-quality service as early and as effectively as possible.

# A Model of Home Intervention for Infant, Toddler, and Preschool Aged Multihandicapped Sensory Impaired Children

## THE INSITE MODEL

## Volume I

The INSITE Model and Information for Parent Advisors

The INSITE Home Visit Program

- Communication
- Hearing

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# A Model of Home Intervention for Infant, Toddler, and Preschool Aged Multihandicapped Sensory Impaired Children

## THE INSITE MODEL

## Volume II

The INSITE Home Visit Program

- Vision
- Cognition
- Motor Impairments
- Developmental Resources

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# Agenda
## INSITE Workshop #1 -- All Onsite Format

Day One

| | |
|---|---|
| 9:00 | Welcome and Agenda |
| 9:45 | Overview/Rationale of INSITE Program and Resource Manual |
| 10:30 | Break |
| 10:45 | Home-Based Programming and the Role of the Parent Advisor in Partnershipping with the Family |
| 11:30 | Teaming or Partnershipping Practicum |
| 12:00 | Lunch |
| 1:00 | Working with Families/Practicum |
| 2:00 | Break |
| 2:15 | Simulation Experiences |
| 3:00 | A Look at the Characteristics of the Population of Children with Sensory Impairments and Multiple Disabilities |
| 4:15 | Dismiss |

Day Two

| | |
|---|---|
| 8:30 | Gathering Information for the IFSP |
| 9:30 | Child Assessment |
| 10:00 | INSITE Checklist |
| 10:15 | Break |
| 10:30 | Communication Overview |
| 10:45 | Creating an Environment that Fosters Communication |
| 11:45 | Lunch |
| 12:45 | Cooperative Learning Activity: Creating a Play Space |
| 1:15 | Informal Communication |
| 2:30 | Break |
| 2:45 | Tangible Symbols |
| 3:00 | Formal Communication |
| 4:00 | Other Communication Methodologies |
| 4:15 | Dismiss |

Day Three

| | |
|---|---|
| 8:30 | Overview of Hearing Program |
| 9:00 | Anatomy and Function of the Hearing Mechanism, Causes and Types of Hearing Loss |
| 10:00 | Break |
| 10:15 | Measuring Hearing Loss |
| 10:45 | Putting on Aids, Establishing Hearing Aid Use |
| 11:00 | Practicum: Audiograms, Parts and Functions of the Hearing Aid, Daily Listening Check |
| 12:00 | Lunch |
| 1:00 | Finish Up Practicum Above and Discussion |
| 1:30 | Auditory Program |
| 2:30 | Summary and Evaluation |
| 2:45 | Planning for Workshop #2 |
| 3:00 | Time With Local Supervisor |
| 3:15 | Dismiss |



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# Agenda
## INSITE Workshop #2 -- All Onsite Format

Day One

| | |
|---|---|
| 9:00 | Welcome and Review |
| 9:30 | Who is the Young Child with Visual Impairment? |
| 10:00 | Anatomy and Function of the Eye |
| 10:30 | Break |
| 10:45 | Eye Disorders and their Functional Implications |
| 11:15 | Formal Visual Testing and Working with Eye Specialists |
| 11:45 | Visual Development |
| 12:15 | Lunch |
| 1:15 | Functional Vision Assessment |
| 1:45 | Demonstration with a Child or Use Video |
| 2:15 | Break |
| 2:30 | Helping the Child Learn to Use Vision |
| 4:30 | Dismiss |

Day Two

| | |
|---|---|
| 8:30 | Normal/Abnormal Motor Development |
| 9:00 | Understanding Posture and Movement Disorder |
| 10:15 | Break |
| 10:30 | Handling, Positioning and Use of Adaptive Equipment |
| 12:00 | Lunch |
| 1:00 | Daily Care Needs and Feeding Practicum |
| 2:30 | Break |
| 2:45 | Orientation and Mobility |
| 3:45 | Tactile |
| 4:15 | Dismiss |

Day Three

| | |
|---|---|
| 8:30 | Cognition |
| 9:45 | Application of the Model **OR** Family and the IFSP Process |
| 10:30 | Break |
| 10:45 | Continue with Above |
| 12:00 | Lunch |
| 1:00 | Finish up the Above |
| 2:00 | Data Collection |
| 2:30 | Summary and Evaluation |
| 2:45 | Where Do We Go From Here? |
| 3:00 | Dismiss |

# APPENDIX E

INSITE Training Format Overview

**Table 1. TRAINING FORMAT OPTIONS**

## ON-SITE FORMAT

### WORKSHOP #1 (3 days)

Background and Rationale

Overview of the INSITE Model

Who is a Parent Advisor?

Working With Families

Family Focused Interview

Who is the Child with Sensory Impairments and Additional Disabilities?

Developmental Assessment

Communication Program
- * Creating an environment that fosters communication
- * Informal communication
- * Formal communication
- * Optional modes

Motor Program
- * Normal/abnormal development
- * Posture and movement disorders
- * Handling and positioning - adaptive equipment
- * Feeding and self-care

Developmental Resources
- * Self-Help
- * Social emotional
- * Gross motor
- * Fine motor

Between-Workshop Assignment

### WORKSHOP #2 (3 days)

Hearing Program
- * Helping parents understand hearing loss
- * Putting on aids and establishing use
- * Managing hearing aids
- * Auditory program

Vision Program
- * Understanding vision loss
- * Functional vision
- * The use of touch and hearing to compensate for vision loss

Cognition Program

Application of the INSITE Model

Data Collection

## HOME-STUDY FORMAT

### WORKSHOP #1 (12 Hours)

PRE-WORKSHOP ASSIGNMENT - Working with Families in Early Intervention

Overview of INSITE and How It Incorporates Family-Centered Programming Principles

Family Focused Interview

Who Are These Children with Sensory Impairments and Additional Disabilities?

Communication Program
- * Creating an environment that fosters communication
- * Informal communication
- * Formal communication
- * Optional modes

Hearing Program
- * Helping parents understand hearing loss
- * Putting on aids and establishing use
- * Managing hearing aids
- * Auditory program

Motor Program
- * Normal/abnormal development
- * Posture and movement disorders
- * Handling and positioning - adaptive equipment
- * Feeding and self-care

How Can INSITE Be Used in Your Program?

### HOME-STUDY ASSIGNMENTS

- * Communication
- * Vision
- * Hearing
- * Motor
- * Cognition

### WORKSHOP #2 (12 Hours)

Questions, Concerns, Review
Sharing Ideas on Use of INSITE
Vision Program
Daily Care
Tactile Development
Cognition Program
Application of INSITE

# APPENDIX F

INSITE National Data Reports: 1991-92, 1993-94, & 1993-94

# INSITE 1991-92 NATIONAL DATA REPORT

SKI*HI INSTITUTE
Department of Communicative Disorders
Utah State University
Logan, Utah 84322-1900

January 15, 1993

INSITE SITES THAT SUBMITTED DATA 1991-1992

GEO Atlanta Area School for the Deaf

NXO New Mexico School for the Deaf Preschool

TAC Dallas RDSPD

TBR Arlington RDSPD

TCR Mesquite RDSPD

TEM McAllen RDSPD

TEN Tennessee School for the Deaf

TXF Texas School for Blind-Outreach

TXP Plano Regional Day School for the Deaf

TXS Five County Cooperative

TXV Victoria RDSPD

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ACKNOWLEDGEMENTS

Many people contributed to this annual INSITE data report and we wish to thank them. First of all, our sincere appreciation to Don Barringer, and other Institute staff members for their wholehearted support. Next, our sincere thanks to the INSITE trainers for training new site personnel in data collection. Finally, and perhaps most importantly, we extend our most sincere appreciation to the children, parents, parent advisors, and administrators who participated in INSITE programming and data reporting.

## INTRODUCTION

Project INSITE is a home intervention delivery model for families of sensory impaired children. The program service delivery system consists of: (1) identification/screening, (2) direct services in the home for handicapped children and their families, (3) support services (e.g., physical therapy, ophthalmological support services), and (4) a program management system. This report contains 1991-92 demographic and child progress data from 11 INSITE replication sites.

## 1.0 DEMOGRAPHIC INFORMATION

Table 1 illustrates demographic data on children participating in the INSITE program during the 1991-92 school year. Information was submitted on 132 children during this time period. The demographic data includes information on the following items:

1. Sex and Race
2. Frequency and Combinations of Handicaps
3. Type and Amount of Hearing Loss
4. Type of Visual Impairment
5. Visual Impairment Combinations and Specific Eye Disorders
6. Age of Suspicion and Identification of Hearing and Visual Impairments
7. Communication Methodology
8. Frequency of Home Visits and Other Services

### 1.1 SEX AND RACE

Table One indicates that 52% of INSITE children are female and 48% are male. A majority (72%) of the participants are Caucasian.

### 1.2 FREQUENCY AND COMBINATIONS OF HANDICAPS

As shown in Table 1, 101 (80%) of the INSITE children have a visual handicap. Niney-one (71%) are hearing impaired, 61 (48%) are mentally retarded, and 102 (79%) are physically impaired. Since INSITE children typically have more than one handicap, these percentages exceed 100%.

Regarding combinations of handicaps, the largest percentage of INSITE children (17%) have visual, hearing, mental, and physical handicaps. The next two largest categories are visual, hearing, and physical handicaps, and hearing and physical with 8% each.

## 1.3 TYPE AND AMOUNT OF HEARING LOSS

Table 1 shows the type of hearing loss and the degree of decibel loss for INSITE children who have a hearing impairment. Complete information was collected on 74 children, of whom 66% have sensorineural losses. Information on degree of hearing loss was collected on 68 children. The degree of unaided decibel loss is variable, ranging from 10 dB to 120 dB. The average unaided loss is 70 dB. The degree of aided loss ranges from 10 dB to 120 dB and the average aided loss is 51 dB.

## 1.4 TYPE OF VISUAL IMPAIRMENT

Information on the type of visual impairment is available on 78 INSITE children in Table 1. As presented, 47 children (60%) have an acuity loss; 43 (55%) muscle imbalance; 15 (19%) field loss and 40 (51%) visual processing disorder. The amount of visual loss was reported on 76 children.

## 1.5 VISUAL IMPAIRMENT COMBINATION AND SPECIFIC EYE DISORDERS

Table 1 shows that many INSITE children have combinations of visual impairments. Twenty-one percent have an acuity loss and muscle imbalance, and 20% have a processing loss. INSITE children also have a wide range of specific eye disorders. The most common specific eye disorder is cortical blindness (35%).

## 1.6 AGE OF SUSPICION AND IDENTIFICATION OF HEARING AND VISUAL IMPAIRMENTS

A major INSITE goal is early identification of vision and hearing handicaps. Early educational intervention is believed to maximize a child's development. In Table 1, data are presented with respect to visual and hearing handicaps. The suspicion of a

visual handicap occurs when the child is an average of 1.6 months of age; the average age of the child's visual loss is identified as 6.7 months. The average time lapse between suspicion and identification is 3.2 months. The suspicion of hearing loss occurs when the child is an average 2.5 months of age; the average age the child's hearing loss is identified is 11.5 months. The average time lapse between suspicion and identification is 4.8 months.

### 1.7 COMMUNICATION METHODOLOGY

When children and their families enter the program, the communication methodology is diagnostic and prescriptive. Thereafter, the children proceed through individualized communication training. As shown in Table 1, of those children whose data was reported on the older data sheets 71% are using signals and cues, 35% of the children are in the diagnostic category, 8% are using formal signs, 11% are using primitive signs, and 11% are using other types of communication methodologies. Of those children whose data was reported using the newer data sheet 82% are using cues, 43% are using gestures, 2% are using aided augmented devices, and 62% are using formal coactive signs.

### 1.8 FREQUENCY OF HOME VISITS AND OTHER SERVICES

Most of the INSITE children (73%) are visited once a week by INSITE parent advisors. In addition to their INSITE home visits, 62% receive educational services, 82% receive physical/occupational therapy, 40% receive speech/hearing therapy, and 36% receive medical/health services.

## 2.0 SUMMARY OF DEMOGRAPHIC CHARACTERISTICS: DESCRIPTION OF THE TYPICAL CHILD

The typical child (let's call her Jane) may have a combination of visual, hearing, and physical impairments. In the area of vision, Jane's type of loss is acuity loss and muscle imbalance. Her visual impairment was suspected at the age of 1.6 months and identified at 6.7 months. Jane's hearing loss is sensorineural and her unaided loss in

decibels is 70. The ages at which her hearing loss was suspected and identified were 2.5 and 11.5 months, respectively. Her current communication method is signals/cues. Jane is visited in the home once a week and receives a variety of non-INSITE services: physical/occupational therapy and educational services.

Table 1

**Basic demographics for INSITE Children 1991-92**

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Sex:** | | | |
| Male | 63 | 48 | 130 |
| Female | 67 | 52 | |
| **Race/National Origin:** | | | |
| Caucasian | 91 | 72 | 127 |
| African American | 21 | 16 | |
| Spanish American | 10 | 8 | |
| Native American | 1 | 1 | |
| Other | 4 | 3 | |
| **Frequency of Handicaps:*** | | | |
| Visual | 101 | 80 | 128 |
| Hearing | 91 | 71 | |
| Mental | 61 | 48 | |
| Physical | 102 | 79 | |
| Emotional | 8 | 6 | |
| Learning | 44 | 34 | |

*Because children may have more than one handicap, percentages exceed 100%

Table 1 (cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Combinations of Handicaps:** | | | |
| Visual, Hearing, Mental, Physical | 22 | 17 | 131 |
| Visual, Hearing, Physical | 10 | 8 | |
| Hearing, Physical | 10 | 8 | |
| Visual, Physical | 9 | 7 | |
| Visual, Hearing, Physical, Learning | 9 | 7 | |
| Visual only | 8 | 6 | |
| Visual, Hearing, Mental, Physical, Learning | 8 | 6 | |
| Hearing, Mental, Physical | 7 | 5 | |
| Visual, Mental, Physical, Learning | 7 | 5 | |
| Visual, Hearing | 6 | 5 | |
| Hearing only | 5 | 4 | |
| Visual, Physical, Learning | 5 | 4 | |
| Visual, Mental, Physical | 4 | 3 | |
| Visual, Learning | 3 | 2 | |
| Visual, Mental, Physical, Emotional, Learning | 3 | 2 | |
| Hearing, Mental | 2 | 2 | |
| Visual, Hearing, Mental | 2 | 2 | |
| Visual, Hearing, Mental, Physical, Emotional | 2 | 2 | |
| Visual, Hearing. Learning | 1 | 1 | |
| Hearing, Mental, Learning | 1 | 1 | |
| Hearing, Mental, Physical, Learning | 1 | 1 | |
| Visual, Emotional, Learning | 1 | 1 | |
| Hearing, Mental, Physical, Emotional, Learning | 1 | 1 | |
| Visual, Hearing, Mental, Physical, Emotional, Learning | 1 | 1 | |

Table (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Hearing Loss (for 66 children with hearing loss):*** | | | |
| Type: | | | |
| Sensorineural | 44 | 60 | 74 |
| Conductive | 7 | 10 | |
| Mixed | 9 | 12 | |
| Processing | 6 | 8 | |
| Sensorineural and Processing | 2 | 3 | |
| Sensorineural and Conductive | 1 | 1 | |
| Mixed and Processing | 1 | 1 | |
| Conductive and Processing | 1 | 1 | |
| Sensorineural and Mixed | 1 | 1 | |
| Conductive and Mixed | 1 | 1 | |
| All | 1 | 1 | |
| **Type and Amount of Hearing Loss (for 66 children with hearing loss)(cont.):*** | | | |
| Amount: Unaided ($\underline{M}$ = 70) | | | |
| No loss (0-24 dB) | 3 | 4 | 68 |
| Mild (25-44 dB) | 12 | 18 | |
| Moderate (45-64 dB) | 13 | 19 | |
| Severe (65-90 dB) | 25 | 37 | |
| Profound (90 + dB) | 15 | 22 | |
| Amount: Aided ($\underline{M}$ = 51) | | | |
| No Loss (0-24 dB) | 1 | 5 | |
| Mild (25-44 dB) | 8 | 40 | |
| Moderate (45-64 dB) | 5 | 25 | |
| Severe (65-90 dB) | 4 | 20 | |
| Profound (90 + dB) | 2 | 10 | |
| **Type and Amount of Visual Loss (for 76 children with hearing loss):*** | | | |
| Type: | | | |
| Acuity Loss | 47 | 60 | 78 |
| Visual Processing Disorder | 40 | 51 | |
| Field Loss | 15 | 19 | |
| Muscle Imbalance | 43 | 55 | |

* Because children may have more than 1 type of reported loss, percentages exceed 100%.

Table 1 (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Visual Loss (for 76 children with hearing loss):*** | | | |
| Amount of Visual Loss: | | | |
| Reported as Visual Level: | | | |
| Totally Blind | 2 | 7 | 28 |
| Child sees a direct source of light (Level 1) | 16 | 57 | |
| Child sees shadows of objects blocking light (Level 3) | 3 | 11 | |
| Child sees movements, fixes/follows (Level 4) | 3 | 11 | |
| Child sees bright colorful toys or objects (Level 5) | 2 | 7 | |
| Child sees dull-colored objects with less distinctive features or contrast (Level 8) | 1 | 4 | |
| Child sees people's actions, routine daily events, different environments (Level 9) | 1 | 4 | |
| Reported as Snellen Acuity Equivalent | | | |
| 20/20 | 1 | 6 | 76 |
| 20/50 | 1 | 6 | |
| 20/70 | 1 | 6 | |
| 20/150 | 1 | 6 | |
| 20/200 | 9 | 50 | |
| 20/300 | 1 | 6 | |
| 20/400 | 2 | 11 | |
| 20/450 | 1 | 6 | |
| 20/800 | 1 | 6 | |

Table 1 (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Visual Loss (for 76 children with visual loss):*** | | | |
| Visual Impairment Combination: | | | |
| Acuity, Muscle Imbalance | 16 | 21 | 76 |
| Processing only | 15 | 20 | |
| Muscle Imbalance only | 8 | 11 | |
| Acuity, Processing | 8 | 11 | |
| Acuity only | 6 | 8 | |
| Acuity, Muscle Imbalance, Field Loss | 5 | 7 | |
| Muscle Imbalance, Processing | 5 | 7 | |
| Acuity, Muscle Imbalance, Field Loss, Processing | 5 | 7 | |
| Acuity, Muscle Imbalance, Processing | 3 | 4 | |
| Acuity, Field Loss, Processing | 3 | 4 | |
| Acuity, Field Loss | 1 | 1 | |
| Muscle Imbalance, Field Loss, Processing | 1 | 1 | |
| **Specific Eye Disorder:*** | | | |
| Retinopathy of Prematurity | 9 | 10 | 89 |
| Strabismus | 23 | 26 | |
| Cataracts | 6 | 7 | |
| Optic Nerve Hypoplasia | 8 | 9 | |
| Cortical Blindness | 31 | 35 | |
| Refractive Error | 6 | 7 | |
| Glaucoma | 2 | 2 | |
| Optic Atrophy | 10 | 11 | |
| Retinal Detachment | 3 | 3 | |
| Other | 43 | 48 | |

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type of Communication Method:** | | | |
| (Older data sheet)* | | | |
| Signals/Cues | 30 | 71 | |
| Diagnostic | 13 | 35 | |
| Formal Signs | 3 | 8 | |
| Primitive Signs | 4 | 11 | |
| Other | 4 | 11 | |
| (Newer data sheet)* | | | |
| Cues | 52 | 82 | |
| Gestures | 19 | 43 | |
| Aided Augmentative Device | 1 | 2 | |
| Formal Coactive Signs | 35 | 62 | |
| **Frequency of Home Visits:** | | | |
| Twice a Week | 1 | 1 | 124 |
| Once a Week | 91 | 73 | |
| Every Other Week | 13 | 10 | |
| Other | 19 | 15 | |
| **Other Non-INSITE Services:*** | | | |
| Educational | 66 | 62 | 97 |
| Physical/Occupational Therapy | 87 | 82 | |
| Speech/Hearing Therapy | 41 | 40 | |
| Medical/Health | 38 | 36 | |
| Mental | 2 | 2 | |
| Other | 14 | 14 | |

* Because children may receive more than one service, percentages exceed 100%

| Demographic Characteristics | Valid Cases | Mean |
|---|---|---|
| Average Age of Suspicion of Visual Loss | 39 | 1.6 months |
| Average Age of Identification of Visual Loss | 35 | 6.7 months |
| Average Time Lapse Between Suspicion and Identification for Visual Loss | 28 | 3.2 months |
| Average Age of Suspicion of Hearing Loss | 36 | 2.5 months |
| Average Age of Identification of Hearing Loss | 46 | 11.5 months |
| Average Time Lapse Between Suspicion and Identification for Hearing Loss | 29 | 4.8 months |

## 3.0 DEVELOPMENTAL DATA

The developmental data includes a description of measures and data analysis and reporting procedures.

### 3.1 DESCRIPTION OF MEASURES

Children in the INSITE program receive regular testing on the Callier-Azusa Developmental Scale. The Callier-Azusa is composed of 18 subscales that are organized according to the following five developmental areas: Motor Development (MD); Perceptual Development (PD); Daily Living (DL); Cognition, Communication, and Language (CCL); and Social Development (SD). The scale is based on observation of the child's behaviors. Each child is observed for at least two weeks after which the scale is completed. After determining a child's raw score, developmental age equivalencies based on normal child development are recorded.

### 3.2 DATA ANALYSIS AND REPORTING PROCEDURES

An inherent problem in the analysis of progress of the very young is maturation. In analyses, it is difficult to "tease out" what is basic maturation and what is progress due to a given educational intervention. Two methods used to determine child progress in the INSITE program are the Callier-Azusa pre/post scores and Proportional Change Indexes.

#### 3.2.1 CALLIER-AZUSA PRE/POST SCORES

One method for controlling for maturation is proposed by Sheehan (1979). He suggests the use of initial testing information as a means by which to predict a child's performance in the future. Using initial testing information, a child's developmental rate can be computed by dividing a child's initial developmental age by the chronological age. The post-intervention chronological age is multiplied by the developmental rate to determine a child's predicted score. For example, if a child has a pretest developmental age of 11 months and a pretest chronological age of 47 months, their developmental rate would be .23. Using the developmental rate, the child's predicted score is 12 when the

post chronological age is 52 months (.23 x 52). This predicted score thus becomes a standard against which to compare actual post-test information. The predicted score represents developmental change due to maturation alone; the actual score represents maturation and developmental change due to treatment. Ideally, the actual score should exceed the predicted score.

A summary of Callier-Azusa data for INSITE children during the 1991-92 year is shown in Table 2.

Table 2

Summary of Callier-Azusa Pre/Post Scores
1991-1992

| | Motor Development (MD) | Perceptual Development (PD) | Daily Living (DL) | Communication, Language (CCL) | Cognition, Social Development (SD) |
|---|---|---|---|---|---|
| Mean: | | | | | |
| Pre | 9.2 | 13.2 | 13.0 | 8.7 | 9.8 |
| Post | 11.4 | 16.8 | 16.0 | 11.6 | 13.2 |
| Predicted | 11.4 | 16.5 | 16.2 | 10.9 | 12.2 |
| Did the actual post-score exceed the predicted score? | yes | yes | yes | no | yes |
| Number of Cases | 52 | 52 | 52 | 52 | 52 |

As shown in Table 2, changes from pre to post are noted across all subtests. The degree of change ranges from 2.2 months for Motor Development to 3.6 months for Perceptual Development. What is particularly important is that all but one post-test value exceed predicted values. This indicates that INSITE children are scoring higher at post-test time than what would be expected due to maturation alone.

### 3.2.2 PROPORTIONAL CHANGE INDEXES

INSITE scores on the Callier-Azusa are next transformed to Intervention Efficiency Indexes (Bagnato & Neisworth, 1980) and are compared against pretest developmental rates for each child in the program. The transformation ultimately yields a Proportional Change Index (PCI). The PCI, as described by Wolery (1983), compares children's rate of development during intervention to rate of development at pretest. The PCI equation is shown below:

$$\frac{\text{Developmental Gain}}{\text{Time in Intervention}} - \frac{\text{Pretest Developmental Age}}{\text{Pretest Chronological Age}} = \text{PCI}$$

**Figure 1: Proportional Change Index**

Children whose rates of development are slower during intervention than at pretest will receive a PCI of less than 1.0. In contrast, children whose rates of development accelerate during intervention will receive a PCI greater than 1.0. Ideally, one would want to see accelerated rates (i.e., greater than 1). Proportional Change Indexes, organized according to the five primary developmental areas of the Callier-Azusa Scale, for INSITE children are shown in Table 3.

Table 3

PROPORTIONAL CHANGE INDEXES
FOR PROJECT INSITE CHILDREN
1991-1992

| | Motor Development (MD) | Perceptual Development (PD) | Daily Living (DL) | Cognition, Communication, Language (CCL) | Social Development (SD) |
|---|---|---|---|---|---|
| N | 51 | 52 | 52 | 52 | 52 |
| Mean PCI | 1.5 | 1.8 | 1.3 | 2.4 | 2.1 |

At a subscale level, the average PCI ranges from 1.3 for Daily Living, to 2.4 for Cognition, Communication, and Language. The average INSITE child shows accelerated growth during INSITE treatment in all developmental areas.

## 4.0 SUMMARY OF DEVELOPMENTAL PROGRESS: PROFILE OF THE TYPICAL INSITE CHILD

Recent assessment data show that our average child (Jane) improved in all areas of the Callier-Azusa Scale and that all but one post-test value exceeded what would have been expected in the absence of treatment. In general, Jane's overall rate of development improved during her INSITE intervention.

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# INSITE 1992-93 NATIONAL DATA REPORT

SKI*HI INSTITUTE
Department of Communicative Disorders
Utah State University
Logan, Utah 84322-1900

May 24, 1994

## INSITE SITES THAT SUBMITTED DATA 1992-1993

Arkansas School for the Deaf

Atlanta Area School for the Deaf

New Mexico School for the Deaf Preschool

Victoria Texas RDSPD

Tennessee School for the Deaf

Texas School for Blind-Outreach

Longview Texas RDSPD

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ACKNOWLEDGEMENTS

Many people contributed to this annual INSITE data report and we wish to thank them. First of all, our sincere appreciation to Don Barringer, and other Institute staff members for their wholehearted support. Next, our sincere thanks to the INSITE trainers for training new site personnel in data collection. Finally, and perhaps most importantly, we extend our most sincere appreciation to the children, parents, parent advisors, and administrators who participated in INSITE programming and data reporting.

## INTRODUCTION

Project INSITE is a home intervention delivery model for families of children who are sensory impaired with additional disabilities. The program service delivery system consists of: (1) identification/screening, (2) direct services in the home for the children and their families, (3) support services (e.g., physical therapy, ophthalmological support services), and (4) a program management system. This report contains 1992-93 demographic and child progress data from 7 INSITE replication sites.

## 1.0 DEMOGRAPHIC INFORMATION

Table 1 illustrates demographic data on children participating in the INSITE program during the 1992-93 school year. Information was submitted on 151 children during this time period. The demographic data includes information on the following items:

1. Sex and Race
2. Frequency and Combinations of Disabilities
3. Type and Amount of Hearing Loss
4. Type of Visual Impairment
5. Visual Impairment Combinations and Specific Eye Disorders
6. Age of Suspicion and Identification of Hearing and Visual Impairments
7. Communication Methodology
8. Frequency of Home Visits and Other Services

### 1.1 SEX AND RACE

Table 1 indicates that 44% of INSITE children are female and 56% are male. A majority (68%) of the participants are Caucasian.

### 1.2 FREQUENCY AND COMBINATIONS OF DISABILITIES

As shown in Table 1, 70% of the INSITE children have a visual disability. Seventy-two percent (72%) are hearing impaired, 54% are mentally retarded, and (75%) are physically impaired. Since INSITE children typically have more than one disability, these percentages exceed 100%.

Regarding combinations of disabilities, the largest percentage of INSITE children (19%) have visual, hearing, mental, and physical disabilities. The next largest category is hearing and physical with 11%.

## 1.3 TYPE AND AMOUNT OF HEARING LOSS

Table 1 shows the type of hearing loss and the degree of decibel loss for INSITE children who have a hearing impairment. Information was collected on 90 children, of whom 59% have sensorineural losses. Information on degree of hearing loss was collected on 66 children. The degree of unaided decibel loss is variable, ranging from 15 Db to 120 dB. The average unaided loss is 68 dB. The degree of aided loss ranges from 10 dB to 100 dB and the average aided loss is 48 dB.

## 1.4 TYPE OF VISUAL IMPAIRMENT

Information on the type of visual impairment is available on 77 INSITE children in Table 1. As presented, 68% of the children have an acuity loss; 42% muscle imbalance; 22% field loss and 44% visual processing disorder. The amount of visual loss was reported on 35 children.

## 1.5 VISUAL IMPAIRMENT COMBINATION AND SPECIFIC EYE DISORDERS

Table 1 shows that many INSITE children have combinations of visual impairments. Twelve percent (12%) have an acuity loss and muscle imbalance, and 23% have an acuity loss. INSITE children also have a wide range of specific eye disorders. The most common specific eye disorder is cortical blindness (23%).

## 1.6 AGE OF SUSPICION AND IDENTIFICATION OF HEARING AND VISUAL IMPAIRMENTS

A major INSITE goal is early identification of vision and hearing disabilities. Early educational intervention is believed to maximize a child's development. In Table 1, data are presented with respect to visual and hearing disabilities. The suspicion of a visual disability occurs when the child is an average of 1.8 months of age; the average

age of the child's visual loss is identified as 10.0 months. The average time lapse between suspicion and identification is 6.8 months. The suspicion of hearing loss occurs when the child is an average 4.1 months of age; the average age the child's hearing loss is identified is 12.7 months. The average time lapse between suspicion and identification is 4.6 months.

### 1.7 COMMUNICATION METHODOLOGY

When children and their families enter the program, the communication methodology is diagnostic and prescriptive. Thereafter, the children proceed through individualized communication training. As shown in Table 1, 70% of the children are using cues, 25% are using gestures, 1% are using aided augmented devices, and 41% are using formal coactive signs.

### 1.8 FREQUENCY OF HOME VISITS AND OTHER SERVICES

Most of the INSITE children (63%) are visited once a week by INSITE parent advisors. In addition to their INSITE home visits, 64% receive educational services, 75% receive physical/occupational therapy, 43% receive speech/hearing therapy, and 30% receive medical/health services.

## 2.0 SUMMARY OF DEMOGRAPHIC CHARACTERISTICS: DESCRIPTION OF THE TYPICAL CHILD

The typical child (let's call him Jim) may have a combination of visual, hearing, and physical impairments. In the area of vision, Jim's type of loss is acuity loss and muscle imbalance. His visual impairment was suspected at the age of 1.8 months and identified at 10.0 months. Jim's hearing loss is sensorineural and his unaided loss in decibels is 68. The ages at which his hearing loss was suspected and identified were 4.1 and 12.7 months, respectively. His current communication method is signals/cues. Jim is visited in the home once a week and receives a variety of non-INSITE services: physical/occupational therapy and educational services.

Table 1

**Basic demographics for INSITE Children**
**1992-93**

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Sex:** | | | |
| Male | 82 | 56 | 147 |
| Female | 65 | 44 | |
| **Race/National Origin:** | | | |
| Caucasian | 96 | 68 | 141 |
| African American | 32 | 22 | |
| Spanish American | 7 | 5 | |
| Native American | 2 | 1 | |
| Other | 4 | 3 | |
| **Frequency of Disabilities:*** | | | |
| Visual | 105 | 70 | 151 |
| Hearing | 108 | 72 | |
| Mental | 81 | 54 | |
| Physical | 113 | 75 | |
| Emotional | 5 | 3 | |
| Learning | 36 | 24 | |

*Because children may have more than one disability, percentages exceed 100%

Table 1 (cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Combinations of Disabilities:** | | | |
| Visual, Hearing, Mental, Physical | 29 | 19 | 150 |
| Hearing, Physical | 16 | 11 | |
| Visual, Hearing, Physical | 13 | 9 | |
| Visual, Mental, Physical | 11 | 7 | |
| Visual, Hearing, Mental, Physical, Learning | 11 | 7 | |
| Visual only | 10 | 7 | |
| Visual, Hearing | 7 | 5 | |
| Hearing, Mental, Physical | 7 | 5 | |
| Hearing, Mental, Physical, Learning | 6 | 4 | |
| Hearing, Mental | 5 | 3 | |
| Hearing only | 4 | 3 | |
| Visual, Physical, Learning | 4 | 3 | |
| Visual, Mental, Physical, Learning | 4 | 3 | |
| Visual, Hearing, Mental, Physical, Emotional, Learning | 4 | 3 | |
| Visual, Physical | 3 | 2 | |
| Visual, Hearing, Physical, Learning | 3 | 2 | |
| Visual, Learning | 2 | 1 | |
| Visual, Mental | 1 | 1 | |
| Visual, Hearing, Mental | 1 | 1 | |
| Mental, Physical | 1 | 1 | |
| Visual, Emotional | 1 | 1 | |
| Hearing, Mental, Learning | 1 | 1 | |
| Hearing, Physical, Learning | 1 | 1 | |

Table (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Hearing Loss (for 90 children with hearing loss):*** | | | |
| Type: | | | |
| Sensorineural | 53 | 59 | 90 |
| Conductive | 9 | 10 | |
| Mixed | 17 | 19 | |
| Processing | 3 | 3 | |
| Sensorineural and Processing | 6 | 7 | |
| Conductive and Processing | 2 | 2 | |
| **Type and Amount of Hearing Loss** | | | |
| Amount: Unaided (M = 68 where numerical hearing loss is known) | | | |
| No loss (0-24 dB) | 8 | 7 | 110 |
| Mild (25-44 dB) | 23 | 21 | |
| Moderate (45-64 dB) | 22 | 20 | |
| Severe (65-90 dB) | 37 | 34 | |
| Profound (90 + dB) | 20 | 18 | |
| Amount: Aided (M = 48 where numerical hearing loss is known) | 3 | 16 | |
| No Loss (0-24 dB) | 6 | 32 | |
| Mild (25-44 dB) | 7 | 37 | |
| Moderate (45-64 dB) | 2 | 11 | |
| Severe (65-90 dB) | 1 | 5 | |
| Profound (90 + dB) | | | |
| **Type and Amount of Visual Loss: *** | | | |
| Type: | | | |
| Acuity Loss | 52 | 68 | 77 |
| Visual Processing Disorder | 34 | 44 | |
| Field Loss | 17 | 22 | |
| Muscle Imbalance | 32 | 42 | |

* Because children may have more than 1 type of reported loss, percentages exceed 100%.

Table 1 (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Visual Loss:** | | | |
| Amount of Visual Loss: | | | 23 |
| Reported as Visual Level: | | | |
| Totally Blind | 4 | 17 | |
| Child sees a direct source of light (Level 1) | 7 | 30 | |
| Child sees indirect sources of light (Level 2) | 2 | 9 | |
| Child sees shadows of objects blocking light (Level 3) | 1 | 4 | |
| Child sees movements, fixes/follows (Level 4) | 1 | 4 | |
| Child sees bright colorful toys or objects (Level 5) | 1 | 4 | |
| Child sees objects with colorful patterns (Level 6) | 2 | 9 | |
| Child sees distinctive features of a person (Level 7) | 1 | 4 | |
| Child sees dull-colored objects with less distinctive features or contrast (Level 8) | 1 | 4 | |
| Child sees people's actions, routine daily events, different environments (Level 9) | 2 | 9 | |
| Child sees one dimensional representations (Level 10) | 1 | 4 | |
| Reported as Snellen Acuity Equivalent | | | 12 |
| 20/50 | 1 | 8 | |
| 20/80 | 1 | 8 | |
| 20/99 | 2 | 17 | |
| 20/200 | 6 | 50 | |
| 20/800 | 2 | 17 | |

Table 1 (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Visual Loss:** | | | |
| Visual Impairment Combination: | | | 77 |
| Acuity only | 18 | 23 | |
| Processing only | 13 | 17 | |
| Acuity, Muscle Imbalance | 9 | 12 | |
| Muscle Imbalance only | 8 | 10 | |
| Acuity, Processing | 6 | 8 | |
| Acuity, Muscle Imbalance, Processing | 5 | 6 | |
| Acuity, Muscle Imbalance, Field Loss, Processing | 5 | 6 | |
| Acuity, Field Loss | 4 | 5 | |
| Acuity, Field Loss, Processing | 3 | 4 | |
| Muscle Imbalance, Field Loss | 2 | 3 | |
| Acuity, Muscle Imbalance, Field Loss | 2 | 3 | |
| Muscle Imbalance, Processing | 1 | 1 | |
| Field Loss, Processing | 1 | 1 | |
| **Specific Eye Disorder:** | | | |
| Retinopathy of Prematurity | 6 | 6 | 96 |
| Strabismus | 13 | 14 | |
| Cataracts | 5 | 5 | |
| Optic Nerve Hypoplasia | 6 | 6 | |
| Cortical Blindness | 22 | 23 | |
| Refractive Error | 13 | 14 | |
| Glaucoma | 2 | 2 | |
| Optic Atrophy | 12 | 12 | |
| Retinal Detachment | 2 | 2 | |
| Other | 39 | 41 | |
| Albinism | 2 | 2 | |
| Tumor | 1 | 1 | |
| Nystagmus | 10 | 10 | |

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type of Communication Method:** | | | |
| Cues | 79 | 70 | 113 |
| Gestures | 28 | 25 | |
| Aided Augmentative Device | 1 | 1 | |
| Formal Coactive Signs | 46 | 41 | |
| **Frequency of Home Visits:** | | | |
| Once a week | 88 | 63 | 140 |
| Every other week | 18 | 13 | |
| Three times a month | 25 | 18 | |
| Once a month | 8 | 6 | |
| Other | 3 | | |
| **Other Non-INSITE Services:*** | | | |
| Educational | 80 | 64 | 126 |
| Physical/Occupational Therapy | 94 | 75 | |
| Speech/Hearing Therapy | 54 | 43 | |
| Medical/Health | 38 | 30 | |
| Mental | 1 | 1 | |
| Other | 16 | 13 | |

* Because children may receive more than one service, percentages exceed 100%

| Demographic Characteristics | Valid Cases | Mean |
|---|---|---|
| Average Age of Suspicion of Visual Loss | 50 | 1.8 months |
| Average Age of Identification of Visual Loss | 42 | 10.0 months |
| Average Time Lapse Between Suspicion and Identification for Visual Loss | 31 | 6.8 months |
| Average Age of Suspicion of Hearing Loss | 50 | 4.1 months |
| Average Age of Identification of Hearing Loss | 55 | 12.7 months |
| Average Time Lapse Between Suspicion and Identification for Hearing Loss | 35 | 4.6 months |

## 3.0 DEVELOPMENTAL DATA

The developmental data includes a description of measures and data analysis and reporting procedures.

### 3.1 DESCRIPTION OF MEASURES

Children in the INSITE program receive regular testing on the Callier-Azusa Developmental Scale. The Callier-Azusa is composed of 18 subscales that are organized according to the following five developmental areas: Motor Development (MD); Perceptual Development (PD); Daily Living (DL); Cognition, Communication, and Language (CCL); and Social Development (SD). The scale is based on observation of the child's behaviors. Each child is observed for at least two weeks after which the scale is completed. After determining a child's raw score, developmental age equivalencies based on normal child development are recorded.

### 3.2 DATA ANALYSIS AND REPORTING PROCEDURES

An inherent problem in the analysis of progress of the very young is maturation. In analyses, it is difficult to "tease out" what is basic maturation and what is progress due to a given educational intervention. Two methods used to determine child progress in the INSITE program are the Callier-Azusa pre/post scores and Proportional Change Indexes.

#### 3.2.1 CALLIER-AZUSA PRE/POST SCORES

One method for controlling for maturation is proposed by Sheehan (1979). He suggests the use of initial testing information as a means by which to predict a child's performance in the future. Using initial testing information, a child's developmental rate can be computed by dividing a child's initial developmental age by the chronological age. The post-intervention chronological age is multiplied by the developmental rate to determine a child's predicted score. For example, if a child has a pretest developmental age of 11 months and a pretest chronological age of 47 months, their developmental rate would be .23. Using the developmental rate, the child's predicted score is 12 when the

post chronological age is 52 months (.23 x 52). This predicted score thus becomes a standard against which to compare actual post-test information. The predicted score represents developmental change due to maturation alone; the actual score represents maturation and developmental change due to treatment. Ideally, the actual score should exceed the predicted score.

A summary of Callier-Azusa data for INSITE children during the 1992-93 year is shown in Table 2.

Table 2

Summary of Callier-Azusa Pre/Post Scores
1992-1993

| | Motor Development (MD) | Perceptual Development (PD) | Daily Living (DL) | Cognition, Communication, Language (CCL) | Social Development (SD) |
|---|---|---|---|---|---|
| Mean: | | | | | |
| Pre | 8.6 | 12.6 | 11.8 | 7.2 | 9.0 |
| Post | 11.2 | 16.1 | 15.8 | 9.8 | 13.0 |
| Predicted | 11.6 | 17.0 | 15.5 | 9.6 | 12.0 |
| Did the actual post-score exceed the predicted score? | no | no | yes | yes | yes |
| Number of Cases | 80 | 80 | 78 | 81 | 81 |

As shown in Table 2, changes from pre to post are noted across all subtests. The degree of change ranges from 2.6 months for Motor Development and Cognition, Communication, Language to 4.0 months for Daily Living and Social Development. What is particularly important is that all but two post-test values exceed predicted values. This indicates that INSITE children are scoring higher at post-test time than what would be expected due to maturation alone.

### 3.2.2 PROPORTIONAL CHANGE INDEXES

INSITE scores on the Callier-Azusa are next transformed to Intervention Efficiency Indexes (Bagnato & Neisworth, 1980) and are compared against pretest developmental rates for each child in the program. The transformation ultimately yields a Proportional Change Index (PCI). The PCI, as described by Wolery (1983), compares children's rate of development during intervention to rate of development at pretest. The PCI equation is shown below:

$$\frac{\text{Developmental Gain}}{\text{Time in Intervention}} \div \frac{\text{Pretest Developmental Age}}{\text{Pretest Chronological Age}} = \text{PCI}$$

**Figure 1: Proportional Change Index**

Children whose rates of development are slower during intervention than at pretest will receive a PCI of less than 1.0. In contrast, children whose rates of development accelerate during intervention will receive a PCI greater than 1.0. Ideally, one would want to see accelerated rates (i.e., greater than 1). Proportional Change Indexes, organized according to the five primary developmental areas of the Callier-Azusa Scale, for INSITE children are shown in Table 3.

Table 3

PROPORTIONAL CHANGE INDEXES
FOR PROJECT INSITE CHILDREN
1992-1993

| | Motor Development (MD) | Perceptual Development (PD) | Daily Living (DL) | Cognition, Communication, Language (CCL) | Social Development (SD) |
|---|---|---|---|---|---|
| N | 78 | 79 | 75 | 80 | 80 |
| Mean PCI | 1.0 | 1.3 | 1.2 | 1.6 | 1.9 |

At a subscale level, the average PCI ranges from 1.0 for Motor Development, to 1.9 for Social Development. The average INSITE child shows accelerated growth during INSITE treatment in nearly all developmental areas.

## 4.0 SUMMARY OF DEVELOPMENTAL PROGRESS: PROFILE OF THE TYPICAL INSITE CHILD

Recent assessment data show that our average child (Jim) improved in all areas of the Callier-Azusa Scale and that all but two post-test values exceeded what would have been expected in the absence of treatment. In general, Jim's overall rate of development improved during his INSITE intervention.

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# INSITE 1993-94 NATIONAL DATA REPORT

SKI*HI INSTITUTE
Department of Communicative Disorders
Utah State University
Logan, Utah 84322-1900

February 15, 1995

## INSITE SITES THAT SUBMITTED DATA 1993-1994

Atlanta Area School for the Deaf

Longview Texas RDSPD

Mesquite RDSPD

Fort Worth Regional School for the Deaf

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Many people contributed to this annual INSITE data report and we wish to thank them. First of all, our sincere appreciation to Don Barringer, and other Institute staff members for their wholehearted support. Next, our sincere thanks to the INSITE trainers for training new site personnel in data collection. Finally, and perhaps most importantly, we extend our most sincere appreciation to the children, parents, parent advisors, and administrators who participated in INSITE programming and data reporting.

## INTRODUCTION

Project INSITE is a home intervention delivery model for families of children who are sensory impaired with additional disabilities. The program service delivery system consists of: (1) identification/screening, (2) direct services in the home for the children and their families, (3) support services (e.g., physical therapy, ophthalmological support services), and (4) a program management system. This report contains 1993-94 demographic and child progress data from 4 INSITE replication sites.

## 1.0 DEMOGRAPHIC INFORMATION

Table 1 illustrates demographic data on children participating in the INSITE program during the 1993-94 school year. Information was submitted on 78 children during this time period. The demographic data includes information on the following items:

1. Sex and Race
2. Frequency and Combinations of Disabilities
3. Type and Amount of Hearing Loss
4. Type of Visual Impairment
5. Visual Impairment Combinations and Specific Eye Disorders
6. Age of Suspicion and Identification of Hearing and Visual Impairments
7. Communication Methodology
8. Frequency of Home Visits and Other Services

### 1.1 SEX AND RACE

Table 1 indicates that 41% of INSITE children are female and 59% are male. A majority (70%) of the participants are Caucasian.

### 1.2 FREQUENCY AND COMBINATIONS OF DISABILITIES

As shown in Table 1, 80% of the INSITE children have a visual disability. Thirty-seven percent (37%) are hearing impaired, 45% have a mental impairment, 6% have an emotional disability, 33% have a learning disability, and 60% are physically impaired. Since INSITE children typically have more than one disability, these percentages exceed 100%.

Regarding combinations of disabilities, the largest percentage of INSITE children (24%) have a visual loss only. The next largest category is visual and physical with 10%.

## 1.3 TYPE AND AMOUNT OF HEARING LOSS

Table 1 shows the type of hearing loss and the degree of decibel loss for INSITE children who have a hearing impairment. Information was collected on 25 children, of whom 68% have sensorineural losses. Information on degree of hearing loss was collected on 21 children. The degree of unaided decibel loss is variable, ranging from 20 Db to 120 dB. The average unaided loss is 73 dB. The degree of aided loss for the 11 aided children ranges from 25 dB to 85 dB and the average aided loss is 51 dB.

## 1.4 TYPE OF VISUAL IMPAIRMENT

Information on the type of visual impairment is available on 59 INSITE children in Table 1. As presented, 73% of the children have an acuity loss; 47% muscle imbalance; 41% field loss and 39% visual processing disorder. The amount of visual loss was reported on 59 children.

## 1.5 VISUAL IMPAIRMENT COMBINATION AND SPECIFIC EYE DISORDERS

Table 1 shows that many INSITE children have combinations of visual impairments. Impairment types were reported for 59 chilren. Seventeen percent (17%) have an acuity loss and muscle imbalance, and 14% have an acuity loss. INSITE children also have a wide range of specific eye disorders. The most common specific eye disorder is retinopathy of prematurity (23%).

## 1.6 AGE OF SUSPICION AND IDENTIFICATION OF HEARING AND VISUAL IMPAIRMENTS

A major INSITE goal is early identification of vision and hearing disabilities. Early educational intervention is believed to maximize a child's development. In Table 1, data are presented with respect to visual and hearing disabilities. The suspicion of a

visual disability occurs when the child is an average of 1.6 months of age; the average age the child's visual loss is identified is 4.1 months. The average time lapse between suspicion and identification is 2.8 months. The suspicion of hearing loss occurs when the child is an average 4.2 months of age; the average age the child's hearing loss is identified is 8.0 months. The average time lapse between suspicion and identification is 3.8 months.

### 1.7 COMMUNICATION METHODOLOGY

When children and their families enter the program, the communication methodology is diagnostic and prescriptive. Thereafter, the children proceed through individualized communication training. As shown in Table 1, 59% of the children are using cues, 29% are using gestures, 2% are using aided augmented devices, and 34% are using formal coactive signs.

### 1.8 FREQUENCY OF HOME VISITS AND OTHER SERVICES

Most of the INSITE children (59%) are visited once a week by INSITE parent advisors. In addition to their INSITE home visits, 43% receive educational services, 76% receive physical/occupational therapy, 35% receive speech/hearing therapy, and 33% receive medical/health services.

## 2.0 SUMMARY OF DEMOGRAPHIC CHARACTERISTICS: DESCRIPTION OF THE TYPICAL CHILD

The typical child (let's call him Jim) may have a combination of visual, hearing, and physical impairments. In the area of vision, Jim's type of loss is acuity loss and muscle imbalance. His visual impairment was suspected at the age of 1.6 months and identified at 4.1 months. Jim's hearing loss is sensorineural and his unaided loss in decibels is 73. The ages at which his hearing loss was suspected and identified were 4.2 and 8.0 months, respectively. His current communication method is signals/cues. Jim is visited in the home once a week and receives a variety of non-INSITE services: physical/occupational therapy and educational services.

Table 1

**Basic Demographics for INSITE Children**
**1993-94**

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Sex:** | | | |
| Male | 46 | 59 | 78 |
| Female | 32 | 41 | |
| **Race/National Origin:** | | | |
| Caucasian | 51 | 70 | 73 |
| African American | 15 | 20 | |
| Spanish American | 5 | 7 | |
| Asian American | 2 | 3 | |
| **Frequency of Disabilities:*** | | | |
| Visual | 62 | 80 | 78 |
| Hearing | 29 | 37 | |
| Mental | 35 | 45 | |
| Physical | 47 | 60 | |
| Emotional | 5 | 6 | |
| Learning | 26 | 33 | |

*Because children may have more than one disability, percentages exceed 100%

Table 1 (cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Combinations of Disabilities:** | | | |
| Visual only | 19 | 24 | 78 |
| Visual, Physical | 8 | 10 | |
| Visual, Mental, Physical | 7 | 9 | |
| Visual, Mental, Physical, Learning | 7 | 9 | |
| Visual, Hearing, Mental, Physical, Learning | 6 | 8 | |
| Hearing only | 5 | 6 | |
| Hearing, Mental, Physical, Learning | 4 | 5 | |
| Hearing, Physical | 3 | 4 | |
| Visual, Hearing | 3 | 4 | |
| Visual, Hearing, Mental, Physical, Emotional, Learning | 3 | 4 | |
| Visual, Mental | 2 | 3 | |
| Visual, Hearing, Mental, Physical | 2 | 3 | |
| Hearing, Physical, Learning | 2 | 3 | |
| Visual, Hearing, Physical | 1 | 1 | |
| Visual, Physical, Learning | 1 | 1 | |
| Mental, Physical | 1 | 1 | |
| Visual, Emotional | 1 | 1 | |
| Visual, Mental, Learning | 1 | 1 | |
| Mental, Physical, Learning | 1 | 1 | |
| Visual, Mental, Physical, Emotional, Learning | 1 | 1 | |

Table (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type of Hearing Loss:** | | | |
| Type: | | | |
| Sensorineural | 17 | 68 | 25 |
| Conductive | 1 | 4 | |
| Mixed | 5 | 20 | |
| Processing | 2 | 8 | |
| **Type and Amount of Hearing Loss** | | | |
| Amount: Unaided (M = 73 where numerical hearing loss is known) | | | |
| No loss (0-24 dB) | 1 | 5 | 21 |
| Mild (25-44 dB) | 2 | 10 | |
| Moderate (45-64 dB) | 4 | 19 | |
| Severe (65-90 dB) | 10 | 48 | |
| Profound (90 + dB) | 4 | 19 | |
| Amount: Aided (M = 51 where numerical hearing loss is known) | | | |
| No Loss (0-24 dB) | 0 | 0 | 11 |
| Mild (25-44 dB) | 4 | 36 | |
| Moderate (45-64 dB) | 4 | 36 | |
| Severe (65-90 dB) | 3 | 27 | |
| Profound (90 + dB) | 0 | 0 | |
| **Type and Amount of Visual Loss: *** | | | |
| Type: | | | |
| Acuity Loss | 43 | 73 | 59 |
| Visual Processing Disorder | 23 | 39 | |
| Field Loss | 24 | 41 | |
| Muscle Imbalance | 28 | 47 | |

* Because children may have more than 1 type of reported loss, percentages exceed 100%.

Table 1 (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Visual Loss:** | | | |
| Amount of Visual Loss: | | | 25 |
| Reported as Visual Level: | | | |
| Totally Blind | 2 | 8 | |
| Child sees a direct source of light (Level 1) | 10 | 40 | |
| Child sees shadows of objects blocking light (Level 3) | 3 | 12 | |
| Child sees movements, fixes/follows (Level 4) | 3 | 12 | |
| Child sees bright colorful toys or objects (Level 5) | 2 | 8 | |
| Child sees distinctive features of a person (Level 7) | 3 | 12 | |
| Child sees dull-colored objects with less distinctive features or contrast (Level 8) | 1 | 4 | |
| Child sees people's actions, routine daily events, different environments (Level 9) | 1 | 4 | |
| Reported as Snellen Acuity Equivalent | | | 10 |
| 20/50 | 1 | 10 | |
| 20/150 | 1 | 10 | |
| 20/200 | 7 | 70 | |
| 20/345 | 1 | 10 | |

Table 1 (Cont.)

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type and Amount of Visual Loss:** | | | |
| Visual Impairment Combination: | | | |
| Acuity, Muscle Imbalance | 10 | 17 | 59 |
| Acuity only | 8 | 14 | |
| Acuity, Muscle Imbalance, Field Loss, Processing | 7 | 12 | |
| Acuity, Field Loss | 7 | 12 | |
| Processing only | 6 | 10 | |
| Muscle Imbalance only | 5 | 8 | |
| Acuity, Processing | 3 | 5 | |
| Acuity, Field Loss, Processing | 3 | 5 | |
| Acuity, Muscle Imbalance, Field Loss | 3 | 5 | |
| Field Loss | 3 | 5 | |
| Acuity, Muscle Imbalance, Processing | 2 | 3 | |
| Muscle Imbalance, Processing | 1 | 2 | |
| Field Loss, Processing | 1 | 2 | |
| **Specific Eye Disorder:*** | | | |
| Retinopathy of Prematurity | 15 | 23 | 66 |
| Strabismus | 9 | 14 | |
| Cataracts | 4 | 6 | |
| Optic Nerve Hypoplasia | 1 | 2 | |
| Cortical Blindness | 10 | 15 | |
| Refractive Error | 4 | 6 | |
| Glaucoma | 2 | 3 | |
| Optic Atrophy | 4 | 6 | |
| Retinal Detachment | 6 | 9 | |
| Other | 41 | 62 | |
| Albinism | 7 | 11 | |

| Demographic Characteristics | Frequency | Percentage | Number of Cases |
|---|---|---|---|
| **Type of Communication Method:*** | | | |
| Cues | 35 | 59 | 41 |
| Gestures | 12 | 29 | |
| Aided Augmentative Device | 1 | 2 | |
| Formal Coactive Signs | 14 | 34 | |
| **Frequency of Home Visits:** | | | |
| Once a week | 43 | 59 | 73 |
| Every other week | 7 | 10 | |
| Three times a month | 19 | 26 | |
| Once a month | 1 | 1 | |
| Other | 3 | 4 | |
| **Other Non-INSITE Services:*** | | | |
| Educational | 23 | 43 | 54 |
| Physical/Occupational Therapy | 41 | 76 | |
| Speech/Hearing Therapy | 19 | 35 | |
| Medical/Health | 18 | 33 | |
| Mental | 2 | 2 | |
| Other | 18 | 33 | |

* Because children may be in more than one category, percentages exceed 100%

| Demographic Characteristics | Valid Cases | Mean |
|---|---|---|
| Average Age of Suspicion of Visual Loss | 49 | 1.6 months |
| Average Age of Identification of Visual Loss | 45 | 4.1 months |
| Average Time Lapse Between Suspicion and Identification for Visual Loss | 40 | 2.8 months |
| Average Age of Suspicion of Hearing Loss | 23 | 4.2 months |
| Average Age of Identification of Hearing Loss | 23 | 8.0 months |
| Average Time Lapse Between Suspicion and Identification for Hearing Loss | 23 | 3.8 months |

## 3.0 DEVELOPMENTAL DATA

The developmental data includes a description of measures and data analysis and reporting procedures. Only one site submitted developmental data for 1993-1994.

### 3.1 DESCRIPTION OF MEASURES

Children in the INSITE program receive regular testing on the Callier-Azusa Developmental Scale. The Callier-Azusa is composed of 18 subscales that are organized according to the following five developmental areas: Motor Development (MD); Perceptual Development (PD); Daily Living (DL); Cognition, Communication, and Language (CCL); and Social Development (SD). The scale is based on observation of the child's behaviors. Each child is observed for at least two weeks after which the scale is completed. After determining a child's raw score, developmental age equivalencies based on normal child development are recorded.

### 3.2 DATA ANALYSIS AND REPORTING PROCEDURES

An inherent problem in the analysis of progress of the very young is maturation. In analyses, it is difficult to "tease out" what is basic maturation and what is progress due to a given educational intervention. Two methods used to determine child progress in the INSITE program are the Callier-Azusa pre/post scores and Proportional Change Indexes.

#### 3.2.1 CALLIER-AZUSA PRE/POST SCORES

One method for controlling for maturation is proposed by Sheehan (1979). He suggests the use of initial testing information as a means by which to predict a child's performance in the future. Using initial testing information, a child's developmental rate can be computed by dividing a child's initial developmental age by the chronological age. The post-intervention chronological age is multiplied by the developmental rate to determine a child's predicted score. For example, if a child has a pretest developmental age of 11 months and a pretest chronological age of 47 months, their developmental rate would be .23. Using the developmental rate, the child's predicted score is 12 when the

post chronological age is 52 months (.23 x 52). This predicted score thus becomes a standard against which to compare actual post-test information. The predicted score represents developmental change due to maturation alone; the actual score represents maturation and developmental change due to treatment. Ideally, the actual score should exceed the predicted score.

A summary of Callier-Azusa data for INSITE children during the 1993-94 year is shown in Table 2.

Table 2

Summary of Callier-Azusa Pre/Post Scores
1993-1994

| | Motor Development (MD) | Perceptual Development (PD) | Daily Living (DL) | Cognition, Communication, Language (CCL) | Social Development (SD) |
|---|---|---|---|---|---|
| Mean: | | | | | |
| Pre | 6.4 | 4.4 | 3.0 | 5.5 | 5.8 |
| Post | 8.2 | 5.7 | 3.8 | 7.2 | 7.2 |
| Predicted | 8.3 | 5.7 | 3.8 | 7.1 | 7.5 |
| Did the actual post-score exceed the predicted score? | no | yes | yes | yes | no |
| Number of Cases | 24 | 24 | 24 | 24 | 24 |

As shown in Table 2, changes from pre to post are noted across all subtests. The degree of change ranges from 0.9 months for Daily Living to 1.8 months for Motor Development. What is particularly important is that all but two post-test values exceed predicted values. This indicates that INSITE children are scoring higher at post-test time than what would be expected due to maturation alone.

### 3.2.2 PROPORTIONAL CHANGE INDEXES

INSITE scores on the Callier-Azusa are next transformed to Intervention Efficiency Indexes (Bagnato & Neisworth, 1980) and are compared against pretest developmental rates for each child in the program. The transformation ultimately yields a Proportional Change Index (PCI). The PCI, as described by Wolery (1983), compares children's rate of development during intervention to rate of development at pretest. The PCI equation is shown below:

$$\frac{\text{Developmental Gain}}{\text{Time in Intervention}} - \frac{\text{Pretest Developmental Age}}{\text{Pretest Chronological Age}} = \text{PCI}$$

**Figure 1: Proportional Change Index**

Children whose rates of development are slower during intervention than at pretest will receive a PCI of less than 1.0. In contrast, children whose rates of development accelerate during intervention will receive a PCI greater than 1.0. Ideally, one would want to see accelerated rates (i.e., greater than 1). Proportional Change Indexes, organized according to the five primary developmental areas of the Callier-Azusa Scale, for INSITE children are shown in Table 3.

Table 3

PROPORTIONAL CHANGE INDEXES
FOR PROJECT INSITE CHILDREN
1993-1994

| | Motor Development (MD) | Perceptual Development (PD) | Daily Living (DL) | Cognition, Communication, Language (CCL) | Social Development (SD) |
|---|---|---|---|---|---|
| N | 24 | 24 | 24 | 24 | 24 |
| Mean PCI | 1.5 | 1.4 | 1.5 | 2.0 | 1.5 |

At a subscale level, the average PCI ranges from 1.4 for Perceptual development, to 2.0 for Cognition, communication, Language. The average INSITE child shows accelerated growth during INSITE treatment in all developmental areas.

## 4.0 SUMMARY OF DEVELOPMENTAL PROGRESS: PROFILE OF THE TYPICAL INSITE CHILD

Recent assessment data show that our average child (Jim) improved in all areas of the Callier-Azusa Scale and that all but two post-test values exceeded what would have been expected in the absence of treatment. In general, Jim's overall rate of development improved during his INSITE intervention.

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# APPENDIX G

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